

Any response to the following document would be welcomed by its author, Kay Zakariasen: [Zakariasen@verizon.net](mailto:Zakariasen@verizon.net), 845-304-9532

May, 2013

To all patients who have had a diagnosis of IC/PBS, patient support groups and other interested parties – health insurance companies, the media, Medicare, various governmental agencies; **A letter sent to three committees of the American Urological Association about the unethical, ineffectual, harmful and unscientific treatment for people diagnosed with IC/PBS; what urologists do not tell patients when they recommend treatment for interstitial cystitis/painful bladder syndrome, (IC/PBS):**

1. **Introduction:** an explanation of why I, a patient, and Dr. Elizabeth Kavalier sent a letter to the American Urological Association about unethical treatment for interstitial cystitis/painful bladder syndrome, IC/PBS, as expressed in the Patient Guidelines, pages 1-8
2. **The letter we sent to the American Urological Association, AUA,** the committees of Ethics, Practice Guidelines and Patient Safety, April May 7, 2013 about urological treatment for IC/PBS: pages 9- 24, and 24-58  
(**Summary of letter:** In short, treatment is unethical because it is not effective, it is harmful, it is unscientific, and there is no realistic disclosure to patients about the nature of treatment, the benefit-to-harm ratio or the alternatives to this treatment, a denial of our legal Patients Rights.)  
**Footnotes to the letter,** pp. 24-31  
**Addendum to the letter; 3 patient stories,** James, Anne and Susie, pages 31-58
3. **The Chairs of these three AUA committees responded to our letter** by e-mail, on 5/7/2013 4:13 PM; you will find this response at the end of the letter to the AUA. As you will see from this response, patients will have to inform other patients, because the AUA does not intend to change the treatment as expressed in the 2011 Practice Guidelines, page 59
4. **My/our response to the AUA committees' e-mailed letter/ response, page 60- 64**

If you, as patients, would like to also tell these Chairs of the Ethics, Practice Guidelines and Patient safety committees what you think of our letter, and your own experience with treatment for IC/PBS, you may request their e-mail addresses from me. Please read Dr. Kavalier's and my letter carefully. [zakariasen@verizon.net](mailto:zakariasen@verizon.net)

## 1. Introduction:

## **Letter to the Directors of three American Urological Association Committees:** Judicial and Ethics Committee, Dr. Lightner, the Practice Guidelines Committee, Dr. Wolf, and the Quality Improvement & Patient Safety Committee, Dr. Clemens

Introduction: In this document you will find a copy of a letter which I, Kay Zakariasen, a patient diagnosed with IC/PBS, and a urologist, Dr. Elizabeth Kavalier, have sent to the Chairs of three committees of the American Urological Association (AUA), the committees on ethics, practice guidelines and patient safety, that is urologists Lightner, Wolf and Clemens, on April 18, 2013. Dr. Kavalier is Clinical Assistant Professor of Urology; Weill Cornell Medical College, Director of Urogynecology; Lenox Hill Hospital; Partner, New York Urological Associates. You will find my story, and the stories of three other people diagnosed with IC/PBS in the body of the letter. These stories reveal outcomes of urological surgeries, and in the case of two, James and Anne, very good outcomes when the causes of their symptoms were diagnosed, and they received appropriate treatment for these – physical therapy for myofascial stricture and for pelvic floor muscle dysfunction (PFMD). These patient stories – 3 of more than 3 dozen patients I interviewed – reveal how patients actually experience urological treatment and other, alternative medical treatments.

Since 2004, when Dr. Elizabeth Kavalier and I launched an online survey of patients diagnosed with IC/PBS, [www.cystitispatientsurvey.com](http://www.cystitispatientsurvey.com), we have endeavored to understand two things: **first**, what is the nature of the treatment which the AUA suggests that urologists offer patients diagnosed with IC/PBS, exactly, and is this treatment safe and effective for patients, and **second**, what diagnoses and treatments have actually improved or cured symptoms?

The attached letter to the AUA committees is an answer to our **first question**, regarding the real nature of treatment and whether it is safe and effective. Answers to this question have motivated us to ask the AUA and individual urologists to stop invasive treatment for these symptoms.

With respect to the **first question**, the answers can be summarized as follows, but for the details and documentation, you will have to read the letter. We have sent this letter to these AUA Committees because our research, our survey of 2000 patients, [www.cystitispatientsurvey.com](http://www.cystitispatientsurvey.com), and the latest urological research also, indicates that urological treatment of patients diagnosed with interstitial cystitis/painful bladder syndrome, IC/PBS, is unethical.

- First, while the diagnostic name remains interstitial cystitis/painful bladder syndrome (IC/PBS), and the symptoms are described as chronic urgency and frequency and bladder pain, which imply a diseased bladder, urologists now disagree about this diagnosis: “Because IC varies so much in symptoms and severity, most researchers believe it is not one, but **several diseases**.”  
<http://kidney.niddk.nih.gov/kudiseases/pubs/interstitialcystitis/#what>

If IC/PBS is not one disease, but many, why are we still being diagnosed with one disease, and treated in the same way, for more than a century, rather than being tested for

various possible causes of our symptoms, and treated or referred accordingly. The answer to our second question will provide a list of many causes of our symptoms, and how they can be treated successfully and noninvasively. See list/table of contents of our next document, below.

- The Guidelines claim that treatment is “therapeutic options,” but actually **treatment is multiple surgeries** intended to be done multiple times to the same patient – often dozens of times, in a trial and error fashion. The treatment we have experienced, and which the Guidelines recommend – instillations of chemicals such as DMSO, Chlorpactin, and many other chemicals, hydrodistentions of the bladder, implants of neurostimulators, Botox injections, are all surgeries – that’s why they hurt so much. These surgeries are done in different ways by different urologists; for example hydrodistention can be a 2 minute procedure, or up to 3 hours, and the water pressure also varies. It is so painful and invasive that the bladder always bleeds, and the patient couldn’t stand hydrodistention without anesthesia. All of these surgeries are a century old tradition in urology and are still recommended in the 2011 Guidelines. The multiple dilations of the urethra, also surgeries, are not mentioned in the Guidelines, but continue to be done to at least 25% of patients, despite a urological study which has called dilation “a quality of care problem in the field of urology.” Urologists in Germany have a very different view of dilation than many urologists in the United States, as you will see in the attached letter. The misleading information, found in the Guidelines, and shaping treatment, is also unethical.
- We now have data from thousands of patients, 2000 patients who filled out our survey, [www.cystitispatientsurvey.com](http://www.cystitispatientsurvey.com), 600 who participated in the urological trial called the Interstitial Cystitis Data Base Study (ICDB), published in 2000, and *likely* hundreds more who participated in the ICCRN and ICCTG trials conducted at NIH/NIDDK, our National Institutes of Health, the department which pertains to urology, the NIDDK. (I say “likely” because I have not been able to get this information from the NIH or other urologists, though these trials have been paid for with our tax money. This research appears to have been literally buried in the NIH “archive,” and is even not available from the authors, despite my querying them.) All of these studies asked patients whether the urological treatments they had experienced helped to improve symptoms, and the results can be stated in the words of the conclusion of the ICDB study - that “**...no current treatments have a significant impact on symptoms with time.**”<sup>i</sup> That is, none of the surgeries are effective – nor are the drugs commonly used. There is only one treatment that some patients found effective, among these trials, - myofascial stricture release, a kind of physical therapy which helps heal tissue damaged by surgeries, or other injuries. There are two patient stories included in this letter to the AUA committees, James and

Anne, who got immense relief from physical therapy for pelvic floor muscle dysfunction and myofascial stricture; one urologist pointed out in his book that as many as 70% of patients diagnosed with IC/PBS may have these issues and benefit from physical therapy. These conditions are two of the diagnoses and the treatments which help many patients. There are many more. The omission of the results of new research from the Guidelines, which describes all treatment as ineffective, is also unethical. If these multiple surgeries are ineffective they are not justified, because all surgery is de facto harmful, and justifiable only if the patient is expected to be much more benefitted by the surgery than harmed, that is the surgical treatments are unethical.

- Harm from these surgeries is discussed in the letter.

To add to the explanation of harm that is in the letter, allow us to say here that: Chronic pain, or what urologists call “painful bladder syndrome” in the Guidelines, and “chronic pelvic pain” in their response to our letter, can sometimes be prevented, especially post surgery chronic pain, but there is no mention of prevention of chronic pain or of unnecessary surgeries in the Guidelines. There are now one hundred million people in the United States with chronic pain, one third of the population; some of these people have been diagnosed with IC/PBS – the symptoms urologists label as IC/PBS are chronic urgency and frequency and chronic pelvic pain. Some cases of chronic pain have been caused by surgeries,<sup>1</sup> according to doctors speaking in a seminar on the brain and pain. <http://www.charlierose.com/view/interview/12670>

Doctors in the United States appear to do more surgeries than any other industrialized country, and numbers of various surgeries done in the US differ from state to state, county to county. [http://www.newyorker.com/reporting/2009/06/01/090601fa\\_fact\\_gawande](http://www.newyorker.com/reporting/2009/06/01/090601fa_fact_gawande) This is an indicator that many of those surgeries are unnecessary. They benefit the doctor’s pocketbook, and status, but harm the patient. Many of these surgeries, such as hysterectomies, the multiple surgeries used to “treat” IC/PBS symptoms, and prostate surgeries are unnecessary- that is the patient will not live longer or have significant improvement of symptoms because of the surgeries, and will experience harm from these unnecessary surgeries. Chronic pain from surgeries is experienced by 10% of patients to 50% of patients, depending on the type of surgery and the skill of the surgeon.<sup>2</sup> Estimates of the percentage of hysterectomies which are not necessary range from 10% to

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<sup>1</sup> seminar hosted by Charlie Rose on the Brain/Pain, episode 11, <http://www.charlierose.com/view/interview/12670>

<sup>2</sup> <http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2806%2968700-X/abstract>

According to the doctors who participated in the seminar hosted by Charlie Rose on the Brain/Pain, episode 11, <http://www.charlierose.com/view/interview/12670>, there are several treatments used, none of which are very successful.

90%.<sup>3</sup> Harm from IC/PBS treatment (multiple surgeries) is discussed in our letter to the AUA, in this document. "Prostate Cancer Surgery Shows No Benefit For Many Men," says the title of the report by Dr. Durado Brooks, of the American Cancer Society. " And, " <sup>4</sup>May 21, 2012, the U.S. Preventive Services Task Force (USPSTF) released final recommendations against prostate-specific antigen (PSA)-based screening for prostate cancer, asserting that there is "moderate or high certainty that the service has no net benefit or that the harms outweigh the benefits," and discouraged the use of the test by issuing it a Grade D rating."<sup>5</sup> The test which has determined whether a patient is told they need their prostate removed has a Grade D rating. Many patients experience impotence and incontinence from prostate surgery – and most will not live longer because of the surgery. Again, many patients will end up with chronic pain from surgeries they don't need, whether urological surgeries, cardio surgeries, cesarean sections, or others. <http://www.npr.org/blogs/health/2012/07/18/156992094/prostate-cancer-surgery-shows-no-benefit-for-many-men>

Is the most harmful treatment, the "final treatment," removal of a patient's bladder, which urologists say is necessary because of "progression of the disease" actually necessary, or

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<sup>3</sup> <http://nwhn.org/hysterectomy> "The United States has the highest rate of hysterectomy in the industrialized world, and according to the Centers for Disease Control and Prevention (CDC), hysterectomy is the second most frequently performed surgical procedure (after cesarean section) for U.S. women. Approximately 600,000 hysterectomies are performed annually in the United States, and approximately 20 million American women have had a hysterectomy [3]. Studies show that anywhere from 10 to 90 percent of hysterectomies performed in the United States are not medically necessary, evidenced by the fact that today, approximately 90 percent of hysterectomies are performed electively [2]. The National Women's Health Network (NWHN) believes that unnecessary hysterectomies have put women at risk needlessly, and that health care providers should recognize the value of a woman's reproductive organs beyond their reproductive capacity and search for hysterectomy alternatives before resorting to life-changing operations. Quoted in the Los Angeles Times, NWHN Executive Director Cindy Pearson says, "I advise any woman who is not in a life-threatening situation to see someone else besides a surgeon to explore nonsurgical options first"

<sup>4</sup> "Prostate Cancer Surgery Shows No Benefit For Many Men," says the title of the report by Dr. Durado Brooks, of the American Cancer Society. "Overtreatment of prostate cancer is a well-recognized phenomenon," and "Observational management (wait and see) has been recommended for some men for over a decade, yet 9 out of 10 U.S. men diagnosed with prostate cancer continue to receive definitive therapy (usually surgery or radiation)." "Prostate surgery has risks and side effects, including incontinence and impotence." This is the harm part of the benefit-to-harm ratio on surgery for a diagnosis of prostate cancer. <http://www.npr.org/blogs/health/2012/07/18/156992094/prostate-cancer-surgery-shows-no-benefit-for-many-men>

And, May 21, 2012, the U.S. Preventive Services Task Force (USPSTF) released final recommendations against prostate-specific antigen (PSA)-based screening for prostate cancer, asserting that there is "moderate or high certainty that the service has no net benefit or that the harms outweigh the benefits," and discouraged the use of the test by issuing it a Grade D rating.

<sup>5</sup> <http://www.npr.org/blogs/health/2012/07/18/156992094/prostate-cancer-surgery-shows-no-benefit-for-many-men>

a total failure, as some deans of urological surgery say, and an unimaginable horror for patients? This treatment is again recommended in the Guidelines. See Susie's story.

- Treatment is not scientific, not evidence based, and is unethical for this reason as well. Urologists leading these three committees of the AUA, in response to this letter, claim that the Guidelines represent "... a rigorous and thorough evidence-based processing of peer-reviewed articles." I countered, urological literature often admits that treatment is not evidence based. Furthermore, is "peer review" evidence? One must ask whether peer review that is not based on scientific evidence, is anything but a common opinion among urologists, an opinion which the latest urological research has contradicted.
- This lack of disclosure of realistic information to patients is a denial of our legal Patients' Rights – the right to information necessary to make informed decisions about whether to agree to treatment. As you read this letter that Dr. Kavalier and I sent to these AUA committees, ask yourself if you were informed of the disagreements among urologists about these issues. I refer you here to the first medical case on record, in the 1950s, which set a precedent for disclosure to patients of accurate information about treatment by doctors,<sup>ii</sup> a case which set a precedent for the development of Patients' Rights in the 1970s.

The answer to our **second question**, what diagnoses and treatments, in addition to physical therapy, actually do provide relief of symptoms, has been partially answered by more than 3 dozen patients who volunteered to be interviewed when I sent out a request to all US support groups in 2009. Our symptoms – chronic urgency and frequency and pelvic pain, do seem to be caused by several different factors, that is there are many causes of these symptoms, and the patients I interviewed told me some of these causes and how they were successfully and noninvasively treated. Many patients eventually turn their backs on urological surgeries because this treatment makes symptoms worse. Then, each patient begins to go to doctors in many different medical specialties, and to other health care providers, and if they're lucky, they get a doctor who understands what is causing their symptoms and how to treat it.

The many causes of the "several diseases," which patients I interviewed have experienced, will be provided to patients in the next month, hopefully. The list of these causes of our symptoms and the noninvasive diagnoses and treatments which really improved symptoms is provided here in the form of the Table of Contents for our second document, a.-h. This is not a complete list, but what several of the 3 dozen patients I interviewed told me had helped, even eliminated symptoms. In our letter to the AUA committees, we have begged them to improve and expand this list. These are the alternatives to treatments that most urologists offer; failure to diagnose



for and treat these other causes of patient symptoms is also unethical, and, obviously, extremely harmful:

**The following might be used as a checklist to bring to a doctor, about what you might want to be tested for:**

- a) **Wait and See:** As the new urological Guidelines say, and good medical principle dictates, initial treatment should be conservative, i.e. noninvasive, and the body should be given a chance to heal itself.<sup>iii</sup> Patient stories: Ruth and Pam
- b) **Is the routine urinalysis working for all patients? More sensitive urinalyses to detect bladder infections may be necessary, but are not usually provided, or even known by urologists.** Urologists may have told you that you don't have an infection – but the standard urinalysis does not pick up all infections, and there are more sensitive urinalyses, specific cultures, (mycoplasma and broth cultures) which have saved these patients from the horrific symptoms of undetected urinary tract infections. You can order the broth culture urinalysis yourself, and ask your urologist to order both the broth culture and the mycoplasma culture. New York Urological Associates in New York City already offers the Mycoplasma urinalysis in their office. Patient stories: Eleanor and Rebecca
- c) **It is becoming more and more clear that many patients diagnosed with IC/PBS have myofascial stricture, and pelvic floor muscle dysfunction (PFMD) caused by surgeries, childbirth, sports injuries and other trauma. These causes of chronic urgency and frequency and pelvic pain can be greatly improved with the appropriate physical therapy by a skilled physical therapist. Because many urologists do not look for these conditions, their patients don't get the appropriate treatment.** One of the urologists who does recognize these conditions says that PFMD “is seen in about 70 percent of IC patients and ....often some of the most pronounced symptoms of IC derive from abnormal muscle activity in this region, rather than from the bladder.” This urologist wrote The Interstitial Cystitis Survival Guide. Patient (and pelvic floor therapist ) stories: James, David Wise, Isa Herrera, Anne and Hope. Anne's story and James' story, in the letter to the AUA, attached, are very good explanations of how this diagnosis and treatment works for some patients.  
<http://www.myofascialrelease.com/resources/articles.aspx>  
<http://www.massagemag.com/News/massage-news.php?id=6745&catid=62&title=t>
- d) **Is the heavy use of antibiotics by urologists for treatment of IC/PBS really necessary and beneficial to patients, or do these antibiotics cause damage to our human microbiome and otherwise preventable diseases? In the words of a recent New York Times Sunday Magazine article, “Disorders in our internal ecosystem – a**

loss of diversity, say, or a proliferation of the ‘wrong’ kinds of microbes – may predispose us to obesity and a whole range of chronic diseases, as well as some infections.” <http://www.nytimes.com/2013/05/19/magazine/say-hello-to-the-100-trillion-bacteria-that-make-up-your-microbiome.html?pagewanted=all&r=0>

The medical specialty of infectious diseases has long recognized that antibiotics cause Candida albicans infection, a fungal disease with many miserable symptoms. The newer, international research project, the Human Microbiome Project, has recently correlated the use of antibiotics since the 1940s and 50s with the explosion of not only obesity, but allergies, asthma, inflammatory bowel disease (IBD), type 1 diabetes, GERD, heart disease, some cancers, many autoimmune diseases; this may be the tip of the iceberg. Is the overuse of antibiotics in urological treatment for IC/PBS causing preventable diseases and some of the unrelenting, cruel symptoms that patients diagnosed with IC/PBS suffer? And what have patients found to be effective treatment?

- e) **How other changes in what we eat have improved patients’ symptoms:** a) acid reduction diet, CM’s story, b) importance of greens diet, Kathy’s story, and c) the IC diet, from the ICA.
- f) **Over the counter supplements and fresh aloe can also reduce symptoms:** Prelief, marshmallow root, quercetin and aloe. Patient stories: Ann, Velma and Inna
- g) **A list of other causes of the symptoms diagnosed as IC/PBS, and noninvasive treatments** for these causes, as discovered by patients and their health care providers virus, allergies, parasites, celiac disease/gluten intolerance, inadequate nutrition, adrenal fatigue, thyroid dysfunction, Candida infection, Gram negative bacterial infection, Chlamydia Trachomatis (STD), environmental toxins.
- h) **Are the symptoms patients feel actually a diseased bladder, a condition implied by the name – interstitial cystitis/painful bladder – or really, often, many medical conditions with symptoms all over the body.** These patients have found effective, noninvasive treatment for these conditions. Patient stories – two pleas that so-called IC/PBS be seen as conditions that involve the whole body: Jennifer and Molly



## 2. Our Letter to three AUA Committees:

To: Directors of the American Urological Association (AUA) Judicial and Ethics Committee, Deborah Lightner, the Practice Guidelines Committee, Dr. J. Stuart Wolf, Jr., and the Quality Improvement & Patient Safety Committee, Dr. J. Quentin Clemens

Regarding: Patients' Rights, human rights, and the Practice Guidelines for diagnosis and treatment of interstitial cystitis/painful bladder syndrome (IC/PBS)

From: a patient, Kay Zakariasen, and from Dr. Elizabeth Kavalier, Clinical Assistant Professor of Urology; Weill Cornell Medical College, Director of Urogynecology; Lenox Hill Hospital; Partner, New York Urological Associates

**Statement of intent regarding this project:** We, the signatories to this letter, want to work with patients, first, all urologists, the AUA, the media, the health insurance companies and other interested parties, to stop all invasive procedures for patients who have chronic symptoms of urgency and frequency and pelvic pain, diagnosed as IC/PBS, or by any other name. A century and a half of this is a century and a half of harm to patients, as described in this letter to 3 AUA committees, and invasive treatment should stop because, as stated in the letter,

1. these procedures are ineffective,
2. they are harmful,
3. there are alternative medical diagnoses and treatments which are successful and noninvasive, according to patients,
4. the treatment for IC/PBS is not evidence based, nor is there realistic disclosure in two definitive documents: Practice Guidelines, 2011, and in Campbell-Walsh Urology, 2011 and virtually no disclosure to patients, about the nature, benefit-to-harm ratio and alternatives to urological treatment,
5. and finally, this treatment paradigm is a breach of Patients' Rights and human rights; this century and a half old tradition of multiple surgeries for each patient should no longer be offered patients.

I am aware that there is some strong language in this letter. I have thought about the wisdom of this at length. I am asking you to reconsider a century and a half old tradition. I have no idea what the intentions have been as no one can read another's heart. But a lot of damage has been done.

## TABLE OF CONTENTS:

**Part I:** Our letter to the Directors of the American Urological Association (AUA) Judicial and Ethics Committee, the Practice Guidelines Committee, and the Quality Improvement & Patient Safety Committee; this letter explains points one through five, in the statement of intent. These Directors are Dr. Deborah Lightner, Ethics, Dr. J. Stuart Wolf, Jr., Guidelines, and Dr. J. Quentin Clemens, Quality and Safety.

Pages 1-13

**Endnotes to the research cited** in the letter to these three AUA Committee Chairs, Pages 14-20

**Part II:** The Addendum to this letter, three patient stories which reveal how patients experience urological treatment for so-called IC/PBS

Pages 1-32

Introduction:

Pages 1-4

**James' story;** short term physical therapy recommended by a urologist eliminates "IC/PBS" symptoms, which are actually caused by pelvic floor dysfunction, a sports injury. Pages 4-6

**Susie's story;** reveals the reality of diversion surgery from the patients' point of view; the surgery repudiated by deans of urologic surgery in 1967 and 2005. Pages 7-17

**Anne's story;** too many antibiotics, too many pelvic surgeries, too many urological surgeries and too many antibiotics cause severe pain, for 16 years; myofascial release reduces pain by 75%, in 8 months: Pages 18-32

**Kay Zakariasen**

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April 18, 2013

To: Directors of the American Urological Association (AUA) Judicial and Ethics Committee, Deborah Lightner, the Practice Guidelines Committee, Dr. J. Stuart Wolf, Jr., and the Quality Improvement & Patient Safety Committee, Dr.J. Quentin Clemens

Regarding: Ethics, Patients' Rights, human rights, and the Practice Guidelines for diagnosis and treatment of interstitial cystitis/painful bladder syndrome (IC/PBS)<sup>iv</sup>

**Dr. J. Stuart Wolf, Jr,**  
Chair, AUA Practice Guidelines Committee  
Professor of Urology, University of Michigan Health System  
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University of Michigan Urology, Floor 3, Room 3875  
1500 E. Medical Center Drive, SPC 5330  
Ann Arbor, MI 48109

You will also receive an e-mail copy.

Dear Doctors Lightner, Wolf and Clemens,

I am writing this letter at the suggestion of Dr. Elizabeth Kavalier of New York Urological Associates. Dr. Kavalier and I together pose a very direct question to three AUA Committees and the urologists they represent: Why do the Practice Guidelines for IC/PBS<sup>v</sup> suggest that urologists continue to employ unethical, unscientific and debunked, extremely invasive, and harmful treatments, including but not limited to repeated instillations of chemicals ( in practice these include DMSO, Clorpactin, heparin, Lidocaine and more), cystoscopy under anesthesia with hydrodistention, implantation of neurostimulator devices, Botox injections, and the “major surgery” of removing the bladder? And, why is there no recommendation against dilation of the urethra, the treatment that has been a “quality of care problem in the field of urology,”<sup>vi</sup> for 9 decades, and still going strong? <sup>vii</sup> (As we shall see, in another country dilation was stopped after only one decade.) In the words of one of the lead authors of the ICDB Study, urological treatment for IC/PBS is irrational.<sup>viii</sup>

This letter has three parts: first, the question of the disclosure of the nature, benefit-to-harm ratio and alternatives to this treatment, and problems of ethics, lack of evidence and disclosure to patients. Second, we will list and discuss 4 reasons why surgical treatment (5 of 6 lines of treatment in the Guidelines) for IC/PBS should be discontinued. (If there is any scientific evidence or patient story which verifies the value of these surgeries, we would be glad to see it.)

And finally we ask your committees, the AUA and all urologists, what your plans are to change this treatment, and express what we feel should be done to address this humanitarian issue. To keep doing these surgeries is a failure to recognize patients' humanity. What is more urgent than the health and integrity of our bodies?

There is no reporting in the literature of the horrific patient experience of this treatment. Therefore, in the Addendum to this letter we provide three patient stories: Anne, Susie, and James.

Statement 10 of the Guidelines summarizes treatment for IC/PBS: "Patients should be educated about normal bladder function, what is known and not known about IC/BPS, the benefits vs. risks/burdens of the available treatment alternatives, the fact that no single treatment has been found effective for the majority of patients, and the fact that acceptable symptom control may require trials of multiple therapeutic options (including combination therapy) before it is achieved. Clinical Principle

However, *the nature of treatment* is not "therapeutic options" but multiple surgeries intended for the same patient, often combined with more multiple surgeries, administered in a trial and error fashion; treatment lines 2 through 6, as described in the first paragraph of this letter, have surgical CPT codes. The *benefits vs. risks/burdens* of these multiple surgeries is not "uncertain," as the Guidelines claim. According to the latest and best urological trials, the ICDB Study<sup>ix</sup> and the ICCRN and ICCTG trials,<sup>x</sup> this treatment is ineffectual. These surgeries are also harmful. Finally, while the Guidelines imply that the only *alternatives* to multiple surgeries are more trial and error surgeries, in fact my own and many patients' experience has been that there are legitimate medical diagnoses and successful, noninvasive treatments for the symptoms urologists call IC/PBS, including physical therapy. Unfortunately, it appears that urological treatment itself (surgeries and antibiotics) is one of the causes of patient symptoms, and the worsening of symptoms. Research from the medical specialties of infectious disease and microbiology (The Human Microbiome Project),<sup>xi</sup> for one thing, point to this.

In the words of one of the key authors of the multicenter ICDB Study (2000), all of these alleged treatments for IC/PBS, and others, are irrational. In other words, the urological treatment for IC/PBS is *not evidence based*, and the information in this letter is *not disclosed to patients*. This is not only a denial of Patients' Rights, but also of human rights;<sup>xii</sup> patients are not provided information adequate for sound medical decisions, and are therefore subjected to unnecessary suffering and pain.

These treatments for IC/PBS fly in the face of the AUA Code of Ethics, which requires practitioners to "...live in strict adherence with its principles ("clinical principles"?) and regulations.... and to place the welfare and rights of my patients above all else."<sup>xiii</sup>

Both the most recent and best urological evidence, and hundreds of reports of patient experiences, in the ICDB, ICCTG and ICCRN trials, in our patient survey and in patient interviews, indicate that it is impossible for urologists to adhere to AUA principles, regulations

or Guidelines, that is treatment lines 2 through 6 of the AUA Guidelines, and at the same time pledge to “place the welfare and rights of my patients above all else.”

Doctors may believe that “standard of medical care” provides a safe harbor from legal liability for the frequent harm caused by standard treatment -- i.e., everyone in the specialty does it, so it’s ok. However, this confidence is misplaced, as the disclaimer in the Guidelines points out.<sup>xiv</sup> Inevitably, as literature proving that this treatment is irrational accumulates, that safe harbor will be destroyed by able counsel, because under the law, doctors are not legally justified in relying on “standard of medical care” or guidelines they “knew or should have known” to be wrong. They are charged with staying current on the medical literature of their specialty, and with taking it into account in their practice. (In fact the Disclaimer of the Guidelines explains that “...AUA guidelines ... do not ... define the legal standard of care.”)<sup>xv</sup> Once this fragile wall of defense is breached, there will be legions of lawsuits. It is only a matter of time. As law suits do not normally change the paradigm or standard algorithm for treatment of a disease, we plan to provide information/disclosure to patients and hope urologists will have a change of heart.

At the end of this letter we ask you what your plans are to remedy this this cruel and unethical treatment of patients. And we list the steps that we would like the AUA and urologists to take.

I am a patient and have experienced what has been the standard of care in urology for 9 decades, that is multiple dilations of the urethra, followed by instillations of silver nitrate, and other chemicals, and the antibiotics that go with each of these surgeries. I presented originally in 1970 with a mild UTI, and was successfully treated with one course of antibiotics. However, I was referred to a urologist and told that my urethra was too narrow (24F). There began the “treatment,” which was 10 dilations and 10 instillations of silver nitrate, a cauterization of my bladder and of course the multiple antibiotics that accompany these multiple surgeries. With the tenth dilation, in 1975, I suddenly had severe and unrelenting abdominal pain, bloating, constipation, urgency, frequency and exhaustion. Finally, realizing there was a causal connection between these invasive treatments and my symptoms, I stepped off this treatment merry-go-round and began to investigate various alternative treatments.

These experiences motivated me to try and find help for the symptoms, the “torture” from which there was no relief. Unscientific urological literature for the past century about these treatments, patient experiences, and criticism within the specialty by some urologists<sup>xvi</sup> also inspired this effort. I have been studying the urological literature about the treatment for IC/PBS for three decades. Finally, Dr. Kavalier and I have worked together since 2003 to survey patients about their experience with these treatments: [www.cystitispatientsurvey.com](http://www.cystitispatientsurvey.com). The first 750 responses from patients (now almost 2000) were analyzed by a team of 3 urologists and a PhD scientist, who were recruited and organized by Dr. Kavalier. One of these urologists, Dr. Jennifer Hill, authored the article summarizing their work, and it was published in Urology in 2008.<sup>xvii</sup> Articles were also written for the Newsletter of the National Women’s Health Network, 2009,<sup>xviii</sup> and the new edition of Our Bodies Ourselves, 2011. I am hopeful that more patients and doctors will cooperate in this way in the future.

Finally, I have learned that both the urological surgeries, accompanied by antibiotics, and a virus caused my chronic symptoms, and I have been successfully treated. And, I learned what is summarized in this letter, points 1 through 4, below, through the reading of the literature and Dr. Kavalier's team analysis of our patient survey.

Finding successful treatment took 3 decades, 3 decades of hell. After the first 6 years of intense pelvic pain following every bite of food I ate, a holistic internist diagnosed the cause. The cause of my pain was not what urologists call "painful bladder syndrome," but a *Candida albicans* infection from antibiotics accompanying urological surgeries for so-called IC/PBS. This *Candida a.* infection in turn caused severe allergies to 130 foods. The treatment, a diet restricting these foods for many years, severely limiting the sugar that *Candida* thrives on, and a low dose of Nystatin for a short time relieved the horrible pelvic pain caused by the antibiotics. Second, what has relieved the chronic urgency and frequency that I suffered from for three decades was the diagnosis of Herpes II virus, and suppression of this virus with L-lysine. This virus, according to the allergist who diagnosed it, was causing disease in my intestine and an end organ response in my bladder.<sup>xix</sup> "Virus" has been mentioned in the urological literature,<sup>xx</sup> as a condition some patients have. Strangely, this treatment has relieved my chronic urgency and frequency by about 90 percent. My life became livable again, in 2003.

The 2000 patients who have now responded to our survey, and the more than three dozen patients I've interviewed (who responded to an e-mail I sent to all patient support groups in the US, in 2009), have reported similar experiences after they turned their backs on urological surgeries and, in utter desperation, went to doctors in many different medical specialties. I will list these alternative diagnoses and successful treatments in point number three of this document. .

Patients have told me that they submitted to urological surgeries because they trusted the practitioners who told them this was necessary – as did I. None of the patients I interviewed had heard of Patients' Rights, nor had I before I started this research. I was familiar with and a participator in the struggle for rights for minorities and women in the 1960s, but I did not understand the urgency of the Patients' Rights movement and the right to and necessity of meaningful disclosure.

This is the effort it has taken for all of us to piece together the disclosure I did not get but had a right to when 3 urologists told me I needed dilations of the urethra. The disclosure all patients have a right to. As far as I know, there were only two studies in the urological literature that seriously questioned the urological protocol of multiple, trial and error surgeries for each patient diagnosed with IC/PBS,<sup>xxi</sup> until the ICDB Study and the ICCRN and ICCTG trials, 2000-2010. I'll get to this.

**The following are 4 major reasons that the treatment for IC/PBS symptoms, as presented in the Guidelines, and practiced by urologists, is unethical, and should not be offered to patients:**



**1. These invasive treatments are ineffective, and therefore unjustified under basic medical principles requiring a positive benefit-to-harm ratio:**

Patients are told, and Statement 10 of the Guidelines states, that if patients agree to trial and error of the “therapeutic options offered,” (what are actually multiple surgeries), eventually there will be “adequate symptom control.” This does not appear to be true, according to urologists’ best evidence, and patient stories.

When I called a leader in the field of IC/PBS treatment to double check this promise of “adequate symptom control” the response was : “Kay, there are many therapies for IC/BPS. It may take one or a combination to be successful in treatment.” This is what the Guidelines say.

However, The Guidelines essentially ignore the results of urologists’ newest and best evidence, evidence gained from listening to those who have experienced the treatments – the patients. The results of the multi-center study, the Interstitial Cystitis Data Base Study (ICDB),<sup>xxii</sup> 2000, and the ICCTG and ICCRN trials, 2000-2010,<sup>xxiii</sup> may be summarized in the words of the conclusion of the ICDB study: “...*no current treatments have a significant impact on symptoms with time.*”<sup>xxiv</sup> (Short term, partial relief for some patients does not justify the harm caused by these surgeries; it does mislead both urologists and patients to keep doing the same surgery.) The ICDB Study involved 600 patients, who were experiencing a total of 183 different kinds of treatment during the four years of the Study. The ICCTG and ICCRN trials recorded patient perceptions of the effect of urological and other treatments. Among the many treatments studied during the ICCTG and ICCRN trials, only myofascial physical therapy alleviated patient symptoms.<sup>xxv</sup>

The results of our survey, [www.cystitispatientsurvey.com](http://www.cystitispatientsurvey.com) agree with the results of the ICDB Study and the ICCTG and ICCRN trials. As a young urologist I interviewed on film in 2002 said, “If anything worked we’d all be doing it.” Instead literally hundreds of “options” are experienced by patients; this is the hallmark of treatment that isn’t working.<sup>xxvi</sup> Either the conclusions of the ICDB, ICCTG and ICCRN trials are wrong, or the promise of adequate symptom control, in Statement 10 of the Guidelines, is wrong.

What is this urological “legacy” of a century and a half of surgery for chronic symptoms of urgency and frequency and pelvic pain; is it worthy of the “respect” urologists imply with the word “legacy”? The legacy is a tragic tradition, “27 Surgeries,”<sup>xxvii</sup> and also “therapeutic options,” which are actually multiple surgeries for each patient.

The tradition/legacy began in the 1870s with intentionally created vesico-vaginal fistulas. After VVF, there have been various forms of cutting and removal of major nerves (1930-1998<sup>xxviii</sup>), debridement of the bladder lining,(1896+), electrical and laser fulguration/cauterization of the bladder, (1922-present), and cutting out pieces of the bladder and “diversion,” (1915 to the present).<sup>xxix</sup> The Guidelines Algorithm lists diversion as the sixth and last “line of treatment.” It is not disclosed to patients that cutting out pieces of the bladder and diversion, “major surgery,” has been described as a “failure” by deans of urological surgery, in 1967 and again in 2005.<sup>xxx</sup>

What urological literature does not ask, is how many women, men and even infants and children,<sup>xxx</sup> have suffered major disabilities and social isolation, from the “27 surgeries,” administered to patients from the 1870s to the present, and also from the multiple surgeries which the Guidelines describe as “treatment options,” the second thru sixth lines of treatment in the Guidelines? This is the question that has plagued me since learning of this urological “legacy.”

Current patient stories tell us a great deal about the misery from this urological protocol for IC/PBS. We have provided three patient stories in the Addendum, because the literature does not provide patient stories, and the latter help us see the results of treatment. These stories demonstrate the urgency of this issue. From 2009 to the present I have interviewed virtually all of the patients who volunteered when I sent an e-mail out to all patient support groups in the United States. *James* was told by 3 urologists that he had IC/PBS. Three surgeries, instillations of chemicals, did not improve his symptoms. The lucky discovery of an apparently rare urologist who understands the role of pelvic floor dysfunction<sup>xxxii</sup> caused by trauma from sports, and the recommendation of physical therapy, eliminated his extremely painful “IC/PBS” symptoms. In other words, these surgeries are ineffective and harmful, and there are alternative treatments that work. *Susie* had urgency and frequency from childhood, and thought little of it. Recommended to a urologist, there followed 28 trial and error surgeries in 2 years, and, finally, diversion. At 34 years of age, Susie had no bladder, there was severe damage to her intestines and other major organs, and extreme suffering. Furthermore, diversion was the beginning of 40 more hospitalizations, with more to come. One can see why Poole and Blaivas called this surgery a failure for patients diagnosed with IC/PBS. *Anne’s story* is one of multiple antibiotics from age 13 on, and multiple abdominal surgeries of questionable necessity. The last surgery, a hysterectomy, preceded the onset of so-called IC/PBS symptoms. This diagnosis led to at least 31 urological surgeries in 16 years. Symptoms worsened from 5 (urgency and frequency) and 8 (pelvic pain), on a scale of 10, to off the scale, as urological surgeries proceeded. From her daughter’s roommate, Anne heard of myofascial release physical therapy. Anne writes a masterful description of this therapy, which is the only treatment that has improved her symptoms, an improvement of 75% since September 2012 when the therapy began. A miracle.

- 2. The second reason that surgical treatment for IC/PBS is unethical and should not be offered to patients, is that these multiple surgeries, described in treatment lines 2 through 6 in the Guidelines, are harmful; both the unnecessary<sup>xxxiii</sup> cutting of tissue and the unnecessary antibiotics - “long term antibiotics,” “preventive” antibiotics, and the multiple antibiotics which accompany unnecessary multiple surgeries - are harmful, based upon the medical literature and the results of our survey and patient interviews.**

Surgery is de facto harmful, and justifiable only when the patient is expected to be benefitted much more than harmed by the surgery.<sup>xxxiv</sup> If the ICDB, ICCTG and ICCRN trials and our patient survey are correct, these surgeries are not effective, and therefore not justifiable.

These multiple surgeries are described as “damaging”<sup>xxxv</sup> to the bladder in Campbell-Walsh Urology. One prominent urologist told me that this damage is “temporary.” But he abruptly

ended our e-mail conversation following the next question I asked him - whether damage from multiples of these surgeries is temporary.

However, if the work of Dr. Daniel Brookoff, is correct, the “damage” caused by the multiple surgeries described in lines of treatment 2 through 5 of the Guidelines and line six, diversion, is neither temporary nor harmless. Dr. Brookoff served on the Board of the Interstitial Cystitis Association and treated many IC/PBS patients for pain. He was recommended to me by a patient. He was an oncologist and co-founder and Medical Director of the Methodist Comprehensive Pain Clinic. Dr. Brookoff explained his research to me in an e-mail conversation. He said that “...traditional urologic treatments (hydrodistention, instillations of caustic chemicals, dilation of the urethra, implants of neuromodulators, Botox and steroid injections, cauterization of the bladder lining, combinations of these, and many more) ...often do more to *ingrain and accelerate* those painful conditions (IC/PBS symptoms) than to relieve them...”<sup>xxxvi</sup> This “damage” appears to create a “disordered healing process,” (and) ... these inflamed nerves can create a pain memory in the spinal cord that cannot be stopped even by removing the organ where the pain seems to be coming from – uterus, prostate or bladder. At this point, the pain is coming from the spinal cord.

Currently, pain memory is described by some neurologists as being in the brain;<sup>xxxvii</sup> regardless, the question is whether these multiple surgeries are causing the worsening of symptoms which patients experience.

According to patients, and the literature, when symptoms worsen, patients are told that this is because of “progression of the disease.” This is a medical opinion, not medical science. The question of whether worsening patient symptoms represent “progression of the disease” or damage from dozens of urological and other pelvic surgeries, as Dr. Brookoff, other medical specialties and physical therapists indicate, is rarely raised in the literature, and when it is, it’s ignored. For example, as we’ve said, both Dr. Pool, in 1967, and Dr. Blaivas, in 2005, described diversion surgery as a “failure.” This surgery continues. Susie’s story, in the addendum to this letter, and the 3 other stories of diversion I have heard cry out for change.

Perhaps even more harmful to patients than multiple surgeries, are the antibiotics that urologists prescribe.

The Guidelines admit to “GI disturbances...” from antibiotic treatment of so-called IC/PBS. And one of the Guideline Statements recommends against long term antibiotic treatment for symptoms called IC/PBS. But “preventive” antibiotics are condoned and the antibiotics that accompany dozens of ineffectual, harmful surgeries for so-called IC/PBS are not questioned. Yet the medical specialties of infectious diseases, and microbiology, that is the Human Microbiome Project (HMP) warn of preventable diseases caused by the overuse of antibiotics; the model for health has been reversed, from killing bacteria, and other micro organisms to “gardening” the microbiome (the bacteria, viruses, fungi etc.) because without a healthy microbiome we cannot survive. A 2012 New Yorker article is a splendid overview.<sup>xxxviii</sup>

Meanwhile, we must recognize that many people in the world suffer from damage to this microbiome, including patients of urologists who treat “IC/PBS.” “GI disturbances...” does not begin to describe a *Candida albicans* infection, which can cause the “leaky gut” and multiple allergies which many patients experience, an iatrogenic disease caused by antibiotics. I don’t know if urologists diagnose vaginal “yeast infections,” one form of *Candida* infection, but intestinal *Candida* infections, or other forms of *Candida* infection seem to be rarely recognized, referred for or treated by urologists; I was told many times by scornful urologists, and other doctors, that I did not have a *Candida albicans* infection.<sup>xxxix</sup> This is many patients’ experience.

“GI disturbances...” also does not describe the overlap between the diseases urologists describe as “associated with”<sup>xl</sup> or “comorbidities of” IC/PBS and the beginning of a list of diseases that the HMP project describes as correlated with the beginning of the use of antibiotics in the 1950s;<sup>xli</sup> the overlap includes allergies and inflammatory-bowel disease and this is likely the tip of the iceberg. Anne, Susie and I all have *Candida albicans* infection, and the allergies that result from the assault on the microbiome with unnecessary antibiotics, many of them prescribed by urologists.

The harm from antibiotics that accompany multiple surgeries and which cause *Candida* infections and many so-called diseases “associated with IC/PBS,” can be treated enough to lessen symptoms. The treatment is essential and very helpful. But no patient has said that they are free of food allergies, for example. This is a lifelong problem. See Anne’s story. Anne almost never eats out, for fear of these allergic reactions, and it is almost impossible to find foods she can eat in a restaurant.”

Thankfully, there are alternatives to the blanket diagnosis of IC/PBS, and to the invasive surgical treatment.

- 3. A third reason that treatment focused on multiple surgeries is harmful to patients is that multiple legitimate medical causes of the symptoms of chronic urgency and frequency and pelvic pain have been ignored. And successful, noninvasive treatment is not being provided for these causes of symptoms. For example, the ICCTG trials revealed that one of the causes of chronic symptoms is myofascial stricture, and that physical therapy for this stricture can significantly reduce patient symptoms.<sup>xlii</sup> Yet the Basic Assessment does not list testing for this. And patients say that there are other causes of their symptoms also; the focus on multiple surgeries seems to blind urologists to these causes and treatments, and patients suffer.**

Urologists have claimed for decades that the cause/s of so-called IC/PBS are unknown.

However, this does not appear to be true. One example of a cause of so-called IC/PBS symptoms surfaced in the only successful trial of all the ICCRN and ICCTG trials – that of myofascial physical therapy. Anne’s & James’ stories illustrate the success of this noninvasive treatment for both pelvic floor dysfunction and myofascial stricture.

Successful treatment of symptoms, I have learned from reading medical literature, and my own and other patients' experience, requires knowing the cause of symptoms. For example, it is well known – among doctors and physical therapists - that surgeries and other traumas, like sports or an accident, cause pelvic floor dysfunction and myofascial stricture, - and what urologists call IC/PBS symptoms, which are chronic urgency and frequency and pelvic pain. *Skillful* physical therapy<sup>xliii</sup> for these conditions often improves symptoms enormously. Please see the footnotes for a physical therapist's explanation and see Anne's and James' stories in the Addendum, to understand how muscle and myofascial problems can mimic IC/PBS and how these conditions can be successfully treated with physical therapy. Even long term pelvic floor dysfunction and myofascial stricture caused by a surgery to "lift" the bladder of one patient, 19 years ago, can be greatly improved, and in the process the patient relieved of agonizing, unrelenting pain; pain suffered for 19 years. This patient and her physical therapist agree that although the treatment can be painful, eventually these tight muscles can be loosened. [Carolyn.Vandyken@LifeMark.ca](mailto:Carolyn.Vandyken@LifeMark.ca)  
The level of skill of the therapist is crucial.

Unfortunately, although "physical therapy" is mentioned several times in the Guidelines, 3 urban physical therapists with large practices tell me that very few of the thousands of urologists in each urban area refer patients on a regular basis. This may be improving a little lately. In France, women have been routinely referred for physical therapy before and after childbirth, and also after pelvic surgeries, for a long time, preventing needless patient suffering.<sup>xliv</sup>

Patients have also been diagnosed for other causes of their chronic urgency and frequency and pelvic pain, and successfully, noninvasively treated. In addition to testing for pelvic floor and myofascial problems, the "Basic Assessment" in the Guidelines algorithm, or first diagnosis of a patient, could and should include testing for all of the medical conditions patients report, which have been successfully treated. I am almost finished with a 100 page document about what 3 dozen patients told me in interviews were the diagnoses and the treatments which greatly improved their symptoms. This will be available on our survey site in a month or two.  
[www.cystitispatientsurvey.com](http://www.cystitispatientsurvey.com)

These diagnoses include, in addition to pelvic floor muscle dysfunction and myofascial stricture, and false negative urinalyses from the "routine urinalysis", or failure to find "microorganisms that are not detected by routine culture methodologies...."<sup>xlv</sup> Patients report that more sensitive urinalyses, such as broth culture and mycoplasma culture helped diagnose an infection that didn't show up on the AGAR plate. Other causes of patient symptoms include Candida albicans infections, systemic acidosis, viruses (my own case), allergies (which virtually every patient I've ever talked to has), parasites, celiac disease/gluten intolerance, inadequate nutrition, adrenal fatigue, thyroid dysfunction, gram negative bacterial infection, Chlamydia Trachomatis (STD), and environmental toxins. Often, patients find they need treatment for more than one of these medical conditions. All these conditions can cause urgency and frequency and pelvic pain, and can be successfully and safely treated. It bears repeating: patients interviewed found enormous relief when these medical causes of their "IC/PBS" symptoms were finally diagnosed and treated. Doubtless there are many more medical causes of so-called IC/PBS symptoms. It is our hope that urologists will discover other treatable causes of IC/PBS, from doing follow up of



patients. Interviews with patients readily reveal what patients have spent months or years looking for – relief - and have eventually discovered.

Perhaps private urological practices could be combined with other practices - allergist, internist, physical therapist or naturopath, for example. These specialists must be experienced and skillful. “Future research” should continue, but patient suffering can be greatly helped NOW.

Failure to diagnose these medical conditions, and focusing on harmful surgeries, prolongs patient misery that is unimaginable to those who haven’t experienced it, and causes unnecessary suffering and expense – to the patient, the spouse, the children, the extended family and friends. When we give up on multiple urological surgeries, each of us has to reinvent the wheel, so to speak, in our desperation for relief. We go from doctor to doctor, in many medical specialties, and to other health care providers, and when the real cause/s of one or more symptoms is finally diagnosed, and treated our lives become worth living again. Anne’s, James’ and Kathy’s stories, in the Addendum.

This two tier treatment – urological and then other medical treatment - not only causes months, years, a lifetime of unnecessary and excruciating pain and disability, as urological surgeries proceed but is also financially very expensive for all the payers – patients, tax payers (Medicare, Medicaid), and health insurance companies (whose premiums are paid for by all the members.) Tragically, some of the patients I’ve interviewed haven’t yet discovered the diagnosis and treatment that will work for them – either they haven’t had the physical strength (because of symptoms, disability), the luck to stumble on the right doctor, or they don’t have the income, the insurance and/or the hope required to pursue this second tier of treatment.

Anne’s story is a good example of the pain and expense involved with this two tier treatment. See Anne’s story in the Addendum to this letter. The onset of symptoms of chronic urgency and frequency and pelvic pain followed a hysterectomy for dysmenorrhea. Urologists diagnosed these symptoms as IC/PBS. There followed 16 years of at least 31 trial and error urological surgeries, as recommended by the Guidelines, and even more antibiotics, of course. And many doctors. Anne’s symptoms became far worse. These urological surgeries (and the trips to many doctors in many specialties) may have cost Anne and her insurance company hundreds of thousands of dollars. It’s hard for patients to know exactly what doctors, hospitals, medical appliance companies etc. have charged their insurance companies, and how much was paid out. But Anne does know that she paid \$25,000. out of pocket for the last 6 urological surgeries she had – 3 series of Botox injections, each combined with lengthy hydrodistentions, and two series of steroid injections. Finally, desperate with pain, Anne listened to information from her daughter’s roommate about her mother’s myofascial physical therapy. Anne tried it and myofascial release has relieved her pain by 75% since she began, in September of 2012. Anne and her health insurance company would have saved at least \$100,000. just on treatment, not to mention other expenses, if the physical therapy had been started immediately, in 1997, by bypassing urological surgeries. The cost of myofascial therapy has been a fraction of the cost of harmful, unnecessary urological surgeries. Patients who have no skilled physiotherapists nearby could be provided money for transportation in addition to the cost of the therapy, and the insurance companies and medicare would still save millions of dollars.



This is one part of the tragic story of unnecessary overuse of surgery for pelvic pain.

The antibiotics that accompany all these unnecessary surgeries may be worse than the surgeries. See Ann's and Susie's stories in the Addendum to this letter.

**4. Urological treatment for IC/PBS is unethical, not only because it's ineffectual and harmful, but also because there is virtually no medical evidence to insure efficacy and safety of the urological treatment for IC/PBS, and because there is a lack of realistic disclosure, either in the Guidelines, or Campbell-Walsh Urology, or to patients.**

The "evidence" offered by the Guidelines is almost all "clinical principle, expert opinion and evidence levels of B and C;" these are not medical science but medical opinion, as urologists know. The multiple surgeries, lines 2 through 5 of treatment in the Guidelines, and also line 6, the "final treatment,"<sup>xlvi</sup> are offered as "options" because the benefit-to-harm (more accurate than "risk," for surgery) is "uncertain." As we've seen, the benefit-to-harm ratio is not only "uncertain," but harmful.

Also, patient interviews have revealed that there is almost no realistic disclosure to patients of the nature, benefit-to-harm ratio and the real, noninvasive alternatives to urological treatment for so-called IC/PBS. Most patients have never heard of "Patients' Rights"<sup>xlvi</sup> or of what they are legally entitled to know before agreeing to urological or any other form of treatment. We have no idea that we can't trust a medical protocol, are not aware that often the bottom line of the surgeon is at odds with what is the best thing for the patient. Many patients also come to urologists in a "fog of pain," and are desperate. These are the reasons we agree to submit to these multiple surgeries. A follow up survey of the 2000 patients who have responded to our patient survey, [www.cystitispatientsurvey.com](http://www.cystitispatientsurvey.com), many of whom provided e-mail addresses, would confirm the lack of disclosure that I hear about from patients. Perhaps NIH could spare the time and small funding to do so.

This failure to disclose, in and of itself, could form the basis of successful legal actions against urologists. That is, even if the assumed safe harbor were to hold up in court (which is extremely doubtful), failure to disclose the risks inherent in these procedures would alone sustain an action, since no "reasonable person" would submit to these procedures if she knew the horrendous results that could occur, and their likelihood. Again, it's only a matter of time until successful suits begin accumulating. (Copies of this letter will be sent to major news outlets and health insurance companies and, very soon, to patients.)

The internet and even major medical centers funded to provide more disclosure to patients often just repeat what the Guidelines say, in the case of IC/PBS. For example, the Dartmouth-Hitchcock Center for Shared Decision Making.<sup>xlvi</sup> The medical literature is a foreign language to patients, and is self-serving and unscientific. Also, patient stories without disclosure often

look, to the patient, the way it is described by the urologist - like “progression of the disease,” rather than the iatrogenic harm it is.

By way of example, I read miles of urological literature in the Library of the New York Academy of Medicine, but found no definition of dilation (nature, benefit-to-harm ratio and alternatives to dilation of the urethra), nor any scientific research regarding the efficacy or safety of this treatment. The same holds for all the other treatments. Finally, in 2004, I learned from a cold call and an interview with a German urologist, that German urological research, in the 1980s, demonstrated that dilation destroys a fish scale pattern of overlapping cells in the lining of the urethra, which is essential to keeping infection out of the urethra and bladder. According to this urologist, dilation, a “medical fad,” was stopped in Germany after one decade, the 1980s. With the exception of about 3 articles, all of the dozens of articles I read about dilation in the American literature were extremely enthusiastic about the concept of widening the urethra – from 1917 through the 1990s. A young urologist I interviewed on film in 2002 told me that he considers dilation “voodoo,” but was surprised to find that it is the “mainstay” of the private practice. About 25% of patients are still getting dilations.<sup>xlix</sup> Yet, here we are, with Guidelines that don’t recommend against a nine decade tradition of dilation of the urethra. Dilation is quick, easy and cheap for the urologist (done in the office), and as the scarring heals, and causes urgency and frequency, the patient returns for more and may end up with a lifetime of these surgeries. Eventually, dilation is not an option but a necessity, to open a urethra scarred shut by multiple dilations, so that the patient can urinate. The literature does not identify dilation as surgery, but it is, and it causes adhesions and myofascial stricture. Instrumentation can and does cause biofilms, as well as regular infections. The young urologist I interviewed said “Dilation probably does no harm.” But dilation, instillations of silver nitrate and antibiotics made my life torture – and three decades of this torture interfered with every aspect of my life. There was relief only because I had the insurance needed to see dozens of doctors, and the luck to find the two who could diagnose the causes of my symptoms, and treat me. Finally, I could again enjoy my life, and do this research. To keep doing the multiple surgeries recommended by the Guidelines is a failure to recognize patients’ humanity. There are alternatives.

In the end, it appears that the rare journal articles among decades of self-serving urological literature were correct. One of these articles, was titled “Ineffectiveness of treatment of urethral syndrome in women,” 1978. Another, about dilation, 1972, was titled “The Rape of the Female Urethra.”<sup>l</sup> And now we have the work of the ICDB, ICCRN and ICCTG trials: “...no current treatments have a significant impact on symptoms with time.”<sup>li</sup> These were brave doctors, and were completely ignored, it appears, by their thousands of colleagues, worldwide.

Why do these harmful, ineffective treatments continue? It is difficult to escape the conclusion that the driving force is medical profit. It has been observed that each IC/PBS patient represents a veritable “annuity,” i.e., a steady stream of income from multiple trial and error surgeries, whereas referring patients for physical therapy is not so advantageous for the urologist. But this is no justification for continuing these harmful practices. We urge you to follow the obligations of professional ethics because it is the right thing to do for your patients. We believe that the alternative will be an endless series of lawsuits, for costs, pain and suffering.

What is your plan to end this tragic century and a half of surgical treatment for IC/PBS?

What we hope your committees will add to the “Basic Assessment” the noninvasive testing of patients for conditions that are listed in this letter, point number three; there could be a checklist of noninvasive tests offered with the first assessment. These are what three dozen patients we’ve interviewed have told us were the medical diagnoses and noninvasive treatments that ended part or all of their symptoms, e.g. myofascial stricture. We hope you will do follow up of your patients, asking what treatment, by any doctor or other health care provider, has really improved their symptoms. Second, we suggest that you recommend a cessation of the multiple surgeries in lines of treatment 2 through 6, explaining that the newest and best urological evidence indicates these surgeries are both ineffective and harmful. Third, we suggest an end to the diagnostic name of IC/PBS because interstitial cystitis and painful bladder syndrome imply a bladder disease, for which there is no evidence. It is physicians’ role to provide evidence based, effective and safe treatment, to change course when necessary to comply with this medical standard, and to reeducate Medicare, Medicaid and insurance carriers, with medical evidence, and by example, about a safe and effective treatment for patients. Disability status for patients could continue, by admitting harm from diagnosis and an old diagnostic and treatment paradigm, as seen in the ICDB, ICCTG and ICCRN trials; many of these patients would surely experience recovery from symptoms, as Anne and James did, with physical therapy, and with the other treatments listed in point three of this document. Then they would no longer require disability status. This should appeal to Medicare.

This is a bitter cup, but it has been a much more bitter cup for patients who have suffered this treatment for a century and a half. It is time to look at new paradigms – preventing damage to the microbiome rather than “killing” it with antibiotics and other drugs, investigating legitimate medical causes and providing known, noninvasive treatments from all the medical specialties to relieve patient symptoms. Patients can be helped NOW. It took doctors 100 years to admit the known cause of childbed fever. They insisted: “Gentlemen don’t kill their patients!” Finally they agreed to wash their hands before the delivery of a baby.<sup>lii</sup> How many mothers never saw their babies, how many babies never saw their mother because of this human arrogance. This scenario is an old and common one in medicine; admission of the problem and a willingness to change are necessary<sup>liii</sup> and an honorable role for doctors.

We are aware that lawsuits, though sometimes just and necessary, do not generally change a medical protocol, and that we will have to take this information to patients. We are determined to pursue this humanitarian effort. Thankfully, it may be that not all urologists agree with this treatment; I’m told that many at the AUA annual meeting where our survey results were presented applauded our patient survey, [www.cystitispatientsurvey.com](http://www.cystitispatientsurvey.com), and the results of the data analysis, which were published in Urology.<sup>liv</sup> We call on you to support this effort to change the treatment.

We hope to hear from you within a month; then we intend to send this letter to major media and insurance companies, patient support groups, interested governmental institutions and other interested parties. copies will be sent out to the media, major health insurance companies and other interested parties. Action is urgent, for the sake of patients.

It is our hope, that this letter will prompt some dramatic reform by urologists. We are available for consultation and discussion.

Yours sincerely,

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Kay Zakariasen,  
retired, Natural History Magazine, AMNH

(signature of KZ)

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Dr. Elizabeth Kavalier,  
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(Signature of Dr. Kavalier)

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<sup>i</sup> (Proper, JK, Schaeffer, Brensinger, Kusek, Nybert, Landis & the ICDB study group, "A Prospective Study of Interstitial Cystitis: Results of Longitudinal Followup of the Interstitial Cystitis Data Base Cohort," *Journal of Urology*, Vol. 163, 1434-1439, concluded after up to 4 years of following almost 600 patients who were experiencing a total of 183 treatments during the study, that "...no current treatments have a significant impact on symptoms with time."

<sup>ii</sup> Sharpe

<sup>iii</sup> Specter, Michael, "The Power of Nothing," The New Yorker, Dec. 12, 2011, p. 30.

<sup>iv</sup> The pain of the Second World War brought many changes in the way we think of human rights, and the Nuremberg Code was the precedent for Patients' Rights. Have we forgotten that careerism, greed, and other human failures<sup>iv</sup> have caused huge and unnecessary pain in every area of life, and even in medical treatment, making legal Patients' Rights necessary? One need only look at the extensive bibliography of a book like Sharpe, Virginia and Faden, Allen I., Medical Harm: Historical, Conceptual and Ethical Dimensions of Iatrogenic Illness, Cambridge University Press, 1998 to see that many doctors, patients and others have worked very hard to try to bring the down the level of medical harm, with the development of RCTs and the concept of evidence based medicine, and with the creation of Patients' Rights. Is a practice built on iatrogenic harm a genuine source of satisfaction, or is helping people something more satisfying?

<sup>v</sup> [http://www.auanet.org/content/guidelines-and-quality-care/clinical-guidelines/main-reports/ic-bps/diagnosis\\_and\\_treatment\\_ic-bps.pdf](http://www.auanet.org/content/guidelines-and-quality-care/clinical-guidelines/main-reports/ic-bps/diagnosis_and_treatment_ic-bps.pdf)

<sup>vi</sup> Santucci, RA, Payne CK, Anger JT, Saigal CS; Urologic Diseases in American Project, "Office dilation of the female urethra: a quality of care problem in the field of urology," *J Urol*, 2008 Nov; 180 (5):2068-75. Epub 2008 Sept. 18

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I, Kay Zakariasen do not give medical advice or engage in the practice of medicine. Kay Zakariasen under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

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vii Santucci, RA, Payne CK, Anger JT, Saigal CS; Urologic Diseases in American Project, "Office dilation of the female urethra: a quality of care problem in the field of urology," J Urol, 2008 Nov; 180 (5):2068-75. Epub 2008 Sept. 18, Lemack GE, Foster B, Zimmern PE, et al. "Urethral dilation in women: a questionnaire-based analysis of practice", Urology 1999; 54(1):37, and Jennifer R. Hill, Ginger Isom-Batz, Georgia Panagopoulos, Kay Zakariasen, Elizabeth Kavalier, "Patient Perceived Outcomes of Treatments Used for Interstitial Cystitis." For Abstract, i.e. short version, click here: <http://dx.doi.org/10.1016/j.urology.2007.09.011> Then click on "Science Direct," and the abstract will come up. For full text of UROLOGY article, [click here](#)

viii Evidence-based outcomes research and randomized clinical trials are needed to define optimal therapeutic regimens until such time as the underlying etiology and pathophysiology of IC is better understood and rational etiologically based therapy can be initiated." The full quote reads: "A disease with a multitude of therapies is often a condition without a truly effective treatment. Historically, very high success rates have been claimed for several treatments for IC. Unfortunately many of these therapies have never been administered to a uniform population of IC patients under the rigorous conditions of a randomized placebo-controlled study (Guideline, 1 or 2 RCTs). High initial success rates in uncontrolled studies have typically not been substantiated when evaluated under more stringent conditions. Consequently, the approach to treatment of patients with IC is largely based on case series, anecdotal evidence, and/or personal experience. In the absence of a generally accepted and effective therapy, a 'trial and error' approach has emerged for the treatment of IC. Subsequent therapy is predicated on prior failures and the patient's and physician's willingness to proceed with increasingly time-consuming, invasive and/or costly treatments. ....physicians tend to add therapies in the event of symptomatic progression or recurrence, rather than change to a different regimen. ...an evidence-based therapeutic algorithm for the treatment of patients with IC, either newly diagnosed or who have failed initial therapy does not exist."

The large number and variety of treatments reported at baseline in women enrolled in the ICDB study reflect both the absence of effective treatments and the lack of knowledge about underlying disease mechanisms. Currently no standardized guidelines for therapy exist for either newly diagnosed patients or those who have failed prior therapy. Evidence-based outcomes research and randomized clinical trials are needed to define optimal therapeutic regimens until such time as the underlying etiology and pathophysiology of IC is better understood and rational etiologically based therapy can be initiated. Rovner, Eric , Probert, KJ, et. al "Treatments used in Women with Interstitial Cystitis: The Interstitial Cystitis Data Base Study Experience" UROLOGY 56 (6), 2000.

ix [https://www.niddkrepository.org/niddkdocs/ICDB/ICDB\\_MOP.pdf](https://www.niddkrepository.org/niddkdocs/ICDB/ICDB_MOP.pdf)

x <http://archives.niddk.nih.gov/patient/iccrn/iccrn.aspx> "This is the first time in a decade of NIDDK-sponsored clinical trials in IC that there has been a positive result," said Dr. Christopher Payne at the American Urological Association (AUA) 2010 Annual Meeting, May 29 – June 3, 2010, San Francisco, CA. The trial that Dr. Payne said was successful was physical therapy, i.e. myofascial physical therapy: Randomized Multicenter Clinical Trial Shows Efficacy of Myofascial Physical Therapy in Women with IC/PBS Payne, C, Fitzgerald, MP, Burks, D, Nickel, C, Lukacz, E, Kreder, K, Chai, T, Hanno, P, Mayer, R, Yang, C, Peters, K, Foster, H, Landis, R, Cen, Probert, K, Kusek, J. American Urological Association (AUA) 2010 Annual Meeting, May 29 – June 3, 2010, San Francisco, CA.

xi [http://scholar.google.com/scholar?q=the+human+microbiome+project&hl=en&as\\_sdt=0&as\\_vis=1&oi=scholar&sa=X&ei=VVZYUc-NJOiy0AGh24DABA&ved=0CCkOgQMwAA](http://scholar.google.com/scholar?q=the+human+microbiome+project&hl=en&as_sdt=0&as_vis=1&oi=scholar&sa=X&ei=VVZYUc-NJOiy0AGh24DABA&ved=0CCkOgQMwAA)

xii [http://www.equalpartners.info/Chapter1/ch1\\_1How.html](http://www.equalpartners.info/Chapter1/ch1_1How.html)

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<sup>xiii</sup> “Statement one of the Code of AUA Ethics: Recognizing that the American Urological Association seeks to exemplify and develop the finest standards of urologic care, I hereby pledge myself, as a condition of membership, to live in strict adherence with its principles and regulations. I pledge myself to pursue the practice of urology with honesty and place the welfare and rights of my patients above all else. I pledge to deal with each patient as I would wish to be dealt with myself. I will render services to humanity with full respect for human dignity, giving full measure of service and devotion, and using my skills to

the very best of my abilities. I pledge myself to cooperate in advancing and extending the art and science of urology by my attentive diligent membership in the American Urological Association.”

<sup>xiv</sup> Disclaimer of Guidelines: “AUA guidelines provide guidance only, and do not establish a fixed set of rules or define the legal standard of care.”

<sup>xv</sup> [http://www.auanet.org/content/guidelines-and-quality-care/clinical-guidelines/main-reports/ic-bps/diagnosis\\_and\\_treatment\\_ic-bps.pdf](http://www.auanet.org/content/guidelines-and-quality-care/clinical-guidelines/main-reports/ic-bps/diagnosis_and_treatment_ic-bps.pdf)

At the end of these Guidelines, just before the “References” section, you will find the full AUA “Disclaimer” of the Guidelines.

<sup>xvi</sup> Two very rare articles, over many decades, which contradicted the benefits of the urological treatment protocol for IC: Pfau A, “The Rape of the Female Urethra”, *Urology Digest* August 11, 1972; and Zufall R, “Ineffectiveness of treatment of urethral syndrome in women”, *Urology*, Sep, 1978; 12(3):337-9.

<sup>xvii</sup> January, 2008: Jennifer R. Hill, Ginger Isom-Batz, Georgia Panagopoulos, Kay Zakariasen, Elizabeth Kavalier, “Patient Perceived Outcomes of Treatments Used for Interstitial Cystitis.” For Abstract, i.e. short version, click here: <http://dx.doi.org/10.1016/j.urology.2007.09.011>

Then click on “Science Direct,” and the abstract will come up.

For full text of UROLOGY article, [click here](#)

<sup>xviii</sup> Newsletter article, March, 2009: Zakariasen, Kay and Hill, Jennifer, “The Treatment and Mistreatment of Chronic Urgency and Frequency – Gathering Women’s Experiences about Interstitial Cystitis.” Click here: <http://nwhn.org/treatment-and-mistreatment-chronic-%E2%80%99Curgency-and-frequency%E2%80%99D-%E2%80%93gathering-women%E2%80%99s-experiences-about-int>

<sup>xix</sup> SLEISINGER AND FORDTRAN’S GASTROINTESTINAL AND LIVER DISEASE: PATHOPHYSIOLOGY/DIAGNOSIS/MANAGEMENT, Editors: Feldman, Mark, Friedman, Lawrence S, Sleisenger, Marvin H, Edition: 7, Saunders, Philadelphia, 2002. Volume: 2, Chapter 90: “Enteric Bacterial Flora and Small Bowel Bacterial Overgrowth Syndrome,” by Clark R. Gregg and Phillip P. Toskes, “Indigenous Microbial Flora of the Alimentary Tract,” 1783, 1784 and 1785 and “Mechanisms of Malabsorption and Diarrhea in Small Bowel Bacterial Overgrowth Syndrome,” 1786, 1787 and 1791.

<sup>xx</sup> Koziol, James A., Douglas C. Clark, Ruben F. Gittes and Eng M. Tan, “The Natural History of Interstitial Cystitis: A Survey of 374 Patients - *The Journal of Urology*, Vol. 149, 465-469, March, 1993. Koziol mentions Epstein Barr virus as one “risk factor” or associated disease. Other authors have mentioned virus also. <http://www.ncbi.nlm.nih.gov/pubmed/?term=Koziol+James+A+Douglas+C+Clark+Ruben+F+Gittes+and+Eng+M+Tan+The+Natural+History+of+Interstitial+Cystitis+A+Survey+of+374+Patients+-+The+Journal+of+Urology+Vol+149+465-469+March+1993>

<sup>xxi</sup> Idem, Pfau and Zufall

<sup>xxii</sup> Probert, JK, Schaeffer, Brensinger, Kusek, Nybert, Landis & the ICDB study group, “A Prospective Study of Interstitial Cystitis: Results of Longitudinal Followup of the Interstitial Cystitis Data Base Cohort,” *Journal of Urology*, Vol. 163, 1434-1439, concluded after up to 4 years of following almost 600 patients who were experiencing a total of 183 treatments during the study, that “...no current treatments have a significant impact on symptoms with time.”



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<sup>xxiii</sup> “This is the first time in a decade of NIDDK-sponsored clinical trials in IC that there has been a positive result,” said Dr. Christopher Payne at the American Urological Association (AUA) 2010 Annual Meeting, May 29 – June 3, 2010, San Francisco, CA. The trial that Dr. Payne said was successful was physical therapy, i.e. myofascial physical therapy: Randomized Multicenter Clinical Trial Shows Efficacy of Myofascial Physical Therapy in Women with IC/PBS Payne, C, Fitzgerald, MP, Burks, D, Nickel, C, Lukacz, E, Kreder, K, Chai, T, Hanno, P, Mayer, R, Yang, C, Peters, K, Foster, H, Landis, R, Cen, Probert, K, Kusek, J. American Urological Association (AUA) 2010 Annual Meeting, May 29 – June 3, 2010, San Francisco, CA.

UCPPS (Urologic Chronic Pelvic Pain Syndrome) trials: ICCTG & ICCRN (NIDDK sponsored, two separate five year grant cycles, the Interstitial Cystitis Clinical Trials Group (ICCTG) and the Interstitial Cystitis Collaborative Research Network (ICCRN)

<sup>xxiv</sup> (Probert, JK, Schaeffer, Brensinger, Kusek, Nybert, Landis & the ICDB study group, ”A Prospective Study of Interstitial Cystitis: Results of Longitudinal Followup of the Interstitial Cystitis Data Base Cohort,” *Journal of Urology*, Vol. 163, 1434-1439, concluded after up to 4 years of following almost 600 patients who were experiencing a total of 183 treatments during the study, that “...no current treatments have a significant impact on symptoms with time.”

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<sup>xxvi</sup> “A disease with a multitude of therapies is often a condition without a truly effective treatment.” Rovner, Eric , Probert, KJ, et. al “Treatments used in Women with Interstitial Cystitis: The Interstitial Cystitis Data Base Study Experience” *Urology*, 56 (6), 2000. And Sant, Grannum, R., MD, *Interstitial Cystitis*, Lippincott-Raven Publishers, Philadelphia, 1997, Chapter One, by Timothy J. Christmas, pp. 1-8. (Christmas – Dept. of Urological Surgery, Charing Cross Hospital, London W6 8RF, United Kingdom.)

<sup>xxvii</sup> Sant, Grannum, R., MD, *Interstitial Cystitis*, Lippincott-Raven Publishers, Philadelphia, 1997, Chapter One, by Timothy J. Christmas, pp. 1-8.

<sup>xxviii</sup> Carter, JE, “Surgical treatment for chronic pelvic pain ,” *JSLs*. 1998 Apr-Jun;2(2): 129-39.

Appell, RA, “Section of Voiding Dysfunction and Female Urology,” *Urology*, 1998 Feb; 51 (2A Suppl; 27-29.

<sup>xxix</sup> INTERSTITIAL CYSTITIS, Ed. Grannum Sant, Lippincott-Raven Publishers, Philadelphia, 1997, Chapter 1, “Historical Aspects of Interstitial Cystitis,” 1-7, Table 4: Review of surgical treatments for IC, p. 7:

<sup>xxx</sup> “Forty years ago (1967)Pool,” the dean of urological surgery at the time, recognized that “surgical treatment had not been the boon many had hoped it would be.” “Diversion of the urine (removal of part or all of the bladder) is not the entire answer to the situation. Removal of the lesion (ulcer) in the bladder has been of no benefit. Likewise, removal of almost the entire mobile portion of the bladder proved to be a failure.” Pool also said “I find it difficult to justify such extensive surgery...with such limited results and for these reasons have not been involved in surgery for IC over the past 3 years.” “Blaivas and colleagues (2005) described ...continent diversion (removal of the bladder) in 76 consecutive patients with benign disease with a mean 9-year follow-up. All 7 patients with the diagnosis of IC

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were classified as failures....” Blaivas is Clinical Professor of Urology at Weill Medical College of Cornell University, Chief of Urogynecology at Lenox Hill Hospital and Medical Director of UroCenter of New York. Hanno, Philip, “Painful Bladder Syndrome/Interstitial Cystitis and Related Disorders,” in Wein AJ (ed.), Campbell-Walsh Urology, 9<sup>TH</sup> edition, Philadelphia: Saunders, 2007, p 345

A third urologist told me in 2010, in confidence, that removal of the bladder and replacing it with a piece of intestine is “a nightmare.”

xxxix “Distal Urethral Stenosis” (“Lyon’s Ring”), a 1969, University of California San Francisco explicit teaching film about the dilation of the urethras of infants and children. Immergut, Mark and G.E. Wahman, “The Urethral Caliber of Female Children with Recurrent Urinary Tract Infections, The Journal Of Urology, Vol. 99, Feb., 1968

xxxix Moldwin, Robert M., MD, F.A.C.S. The Interstitial Cystitis Survival Guide, New Harbinger Publications, Inc., 2000. Contains myofascial release, pelvic floor therapy. Robert Moldwin estimates that 75-80% of IC or PBS is caused by pelvic floor muscle dysfunction.

xxxix Sharpe, Virginia A., and Al Faden, Medical Harm: Historical, Conceptual and Ethical Dimensions of Iatrogenic Illness, Cambridge University Press, Cambridge, 1997, Chapter 9, “Unnecessary Surgery.”

xxxix Sharpe, Virginia A., and Al Faden, Medical Harm: Historical, Conceptual and Ethical Dimensions of Iatrogenic Illness, Cambridge University Press, Cambridge, 1997, pp 65-67, 74, 71, 83, 127.

xxxix Hanno, PM, “Painful Bladder Syndrome/Interstitial Cystitis and Related Disorders,” in Wein AJ (ed), CAMPBELL –WALSH UROLOGY, 9<sup>th</sup> Edition, Philadelphia: Saunders, 2007, p 345, “Key point,” p. 6 of online edition: “Treatments that tend to damage GAG (“increased permeability” of the inner lining of the bladder) including transurethral resection and laser of ulcerated areas, bladder distention (hydrodistention under general anesthesia, used as both a diagnosis and treatment), silver nitrate administration and oxychlorosene (Clorpectin) administration and use the organic solvent dimethyl sulfoxide (DMSO) have all been used with varying results to treat IC.

xxxix Brookoff, Daniel, Chapter 28, “Genitourinary Pain Syndromes: Interstitial Cystitis, Chronic Prostatitis, Pelvic Floor Dysfunction, and Related Disorders,” CURRENT THERAPY IN PAIN, H.S. Smith (editor). Saunders-Elsevier; Philadelphia; 2009, pp. 205-215.

Brookoff, Daniel, Hospital Practice; July 15, 2000; vol 35 pages 45-59

<file:///Users/danielbrookoff/Desktop/Hospital%20Practice-%20Chronic%20Pain.webarchive> Page 1 of 10

xxxix [http://www.charlierose.com/view/interview/12670?sponsor\\_id=1](http://www.charlierose.com/view/interview/12670?sponsor_id=1) The role of the brain and chronic pain, was discussed on the Charlie Rose Series on the brain, Episode 11 with David Julius, David Borsook, Robert Dworkin, Laurie Klein, Eric Kandel and Allan Basbaum, Friday, November 23, 2012.

xxxix [http://www.newyorker.com/reporting/2012/10/22/121022fa\\_fact\\_specter](http://www.newyorker.com/reporting/2012/10/22/121022fa_fact_specter)

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<sup>xxxix</sup> Mandell, Douglas And Bennett's Principles And Practice Of Infectious Diseases, sixth edition, Volume 2, Elsevier, Churchill, Livingstone, 2004, Chapter 255, "Candida Species," pp. 2935-2956 Mandell: Mandell, Douglas and Bennett's Principles and Practice of Infectious Diseases, 7<sup>th</sup> ed., 2009 Churchill Livingstone, An imprint of Elsevir, Chapter 257, Candida Species, John E. Edwards, Jr., pp. 3225-3240.

<sup>xl</sup> In CampbellWalsh Urology, 10<sup>th</sup> Edition, 2011, pp. 365-366 under "Epidemiology," the list of diseases "associated with" IC/PBS are:

Allergies – 41 % of patients with an IC diagnosis also have a diagnosis of allergies and 45% have allergic symptoms

IBS - 30% of patients had a diagnosis of irritable bowel syndrome (IBS)

Fibromyalgia is also overrepresented in the IC community,

Systemic lupus erythematosus is often seem as more common in IC patients

Inflammatory bowel disease (IBD) is found in over 7% of the IC population, 100 times higher than in the general population

Siogren's syndrome appears to be more prevalent than in the general population.<sup>xl</sup>

<sup>xli</sup> The Human Microbiome Project, has recently correlated the use of antibiotics since the 1940s and 50s with the explosion of diseases such as allergies, asthma, inflammatory bowel disease (IBD), obesity, type 1 diabetes, GERD, and many autoimmune diseases; this is likely the tip of the iceberg. <sup>xli</sup>

[http://www.nytimes.com/2011/11/01/health/scientist-examines-possible-link-between-antibiotics-and-obesity.html?\\_r=1](http://www.nytimes.com/2011/11/01/health/scientist-examines-possible-link-between-antibiotics-and-obesity.html?_r=1)

"Dr. David Relman, Stanford University, studies the microbiome of the mouth and intestines. The richest microbiome in the body may be in the intestines, and the effect of antibiotics on this system is still largely unknown but enormous and important. He also briefly discusses what is known and unknown about the ability of probiotics to replace essential bacteria and bacterial balance which is lost when antibiotics kill part of the biome.

<http://www.dnatube.com/video/6971/David-Relman-The-Stability-of-the-Human-Microbiome-MWV51>

<sup>xlii</sup> Idem, Payne

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<sup>xliii</sup> One physical therapist, Carolyn Vandyken, who has helped more than one patient I've interviewed, explains the importance of skillful physical therapy: First, she explains new thinking about chronic pain, as described by Lorimer Moseley, [bodyinmind.org](http://bodyinmind.org). Broadly speaking, "There are patients that need to have tissue work done, and there are patients that are more centrally sensitized (the pain tune in the brain that keeps on playing even though the tissues might be healed), and then there are patients who have a combination of both.

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"Chronic pain is very complex, and as difficult as it may be, it's important to be able to determine what a patient needs. For some, with further medical input into the tissues, like surgery, physical therapy, medication, etc, addressing specific tissue problems (like bladder lining issues, tight muscles, etc), these interventions can sensitize the nervous system further, creating more pain rather than relieving pain. If the brain feels that the intervention is a threat, and the system needs more protection, the patient's pain will worsen, not improve. This is called central sensitization, and the treatment approach needs to be at the brain level, both with medication, but, more importantly with rehabilitation efforts aimed at the brain; the tissues that need to be targeted are the synapses and the neurons in the brain, not so much the tissues in the bladder and pelvic floor. Two examples of retraining the brain are cognitive behavioral training and graded motor imagery.

"Other patients need physical therapy directly, for tense myofascial tissue, and tissues in the bladder and pelvic floor. And "Some patients need both types of therapy."

This physical therapist said that there is "One thing that the majority of health professionals will agree with, is that surgery is not recommended for chronic pain. <sup>xliii</sup>

<sup>xliv</sup> Dr. Jacques Moritz, Director of Obstetrics and Gynecology Division, St. Luke's Roosevelt Hospital, New York, says in the introduction to pelvic floor therapist Isa Herrera's book, Ending Female Pain: a woman's manual: the ultimate self-help guide for women suffering from chronic pelvic and sexual pain.<sup>xliv</sup> "After a woman has a baby, a pelvic surgery or experiences painful intercourse, often no effort is made to eliminate the pain or to test whether her pelvic floor muscles function properly. In other countries like France, for example, pelvic rehabilitation is considered an integral part of the healing process post-childbirth and pelvic surgery. It only makes sense to treat trauma to a very delicate area the same way a broken leg requires therapy."

<sup>xlv</sup> Hanno, "Painful Bladder Syndrome/Interstitial Cystitis and Related Disorders, in CampbellWalsh Urology, 9<sup>th</sup> Edition, Alan Wein, Alan J Wein, Walsh, Louis R Kavoussi, Andrew C Novick, Alan W Partin, Craig A Peters, 2007, "What was originally considered a bladder disease is now considered a chronic pain syndrome (Janicki, 2003) that may begin as a pathologic process in the bladder...PBS/IC encompasses a major portion of the 'painful bladder' disease complex, which includes a large group of patients with bladder and/or urethral and/or pelvic pain, irritative voiding symptoms (urgency, frequency, nocturia, dysuria), and sterile urine cultures. Painful bladder conditions with well established causes include radiation cystitis, cystitis caused by microorganisms that are not detected by routine culture methodologies, and systemic disorders that affect the bladder. In addition, many gynecologic disorders can mimic PBS/IC. (Kohli et al, 1997; Howard 2003a, 2003b p. 330.

<sup>xlvi</sup> Interstitial Cystitis, Ed. Grannum Sant, Lippincott-Raven Publishers, Philadelphia, 1997, Chapter 1, "Historical Aspects of Interstitial Cystitis," 1-7, Table 4: Review of surgical treatments for IC, p. 7:

<sup>xlvii</sup> Sharpe and Faden, pp. 65-67, 74

<sup>xlviii</sup> I called the Dartmouth-Hitchcock Center for Shared Decision Making in August of 2012, because I understood that they provided information for patients on how to make better medical decisions for many medical conditions. Regarding treatment for IC/PBS, I was told that they had no information about this treatment, and referred to the Urology division of the medical school and treatment center. What the Urology department referred me to was the AUA Practice Guidelines for treatment of IC/PBS.

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<sup>xlix</sup> Santucci, RA, Payne CK, Anger JT, Saigal CS; Urologic Diseases in American Project, "Office dilation of the female urethra: a quality of care problem in the field of urology," J Urol, 2008 Nov; 180 (5):2068-75. Epub 2008 Sept. 18, Lemack GE, Foster B, Zimmern PE, et al. "Urethral dilation in women: a questionnaire-based analysis of practice", Urology 1999; 54(1):37, and Jennifer R. Hill, Ginger Isom-Batz, Georgia Panagopoulos, Kay Zakariasen, Elizabeth Kavalier, "Patient Perceived Outcomes of Treatments Used for Interstitial Cystitis." For Abstract, i.e. short version, click here: <http://dx.doi.org/10.1016/j.urology.2007.09.011> Then click on "Science Direct," and the abstract will come up.

For full text of UROLOGY article, [click here](#)

<sup>l</sup> Zufall R, "Ineffectiveness of treatment of urethral syndrome in women", Urology, Sep, 1978; 12(3):337-9. Pfau A, "The Rape of the Female Urethra", Urology Digest August 11, 1972; Rovner, Eric, Propert, KJ, et. al "Treatments used in Women with Interstitial Cystitis: The Interstitial Cystitis Data Base Study Experience" UROLOGY 56 (6), 2000.

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<sup>lii</sup> Burch, Druin, Natural History; Feb 2009, Vol. 118 Issue 1, p6. <http://www.livescience.com/3210-childbirth-natural-deadly.html>

## Addendum; Patient Stories

The interviewer and writer of this document is Kay Zakariasen.

Kay Zakariasen and patients represented here, who have pseudonyms for the purpose of privacy, do not give medical advice or engage in the practice of medicine. Kay Zakariasen and the patients whose stories are in this addendum to a letter to three Committees of the AUA, under no circumstances recommend particular treatment for specific individuals and in all cases recommend that you consult your physician or local treatment center before pursuing any course of treatment.

I have used quotation marks to indicate patients' own words. My comments are not in quotation marks.

### Introduction:

Patient stories tell us a great deal about how patients experience the "therapeutic options" recommended by the AUA Treatment Guidelines for IC/PBS (2011). This is not in the medical literature. Patient stories also reveal some medical causes of symptoms, and noninvasive treatments for these symptoms. Alternatives to trial and error urological surgeries include those offered by other medical specialties and health care providers, including but not only physical

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therapists. These stories are essential for realistic disclosure of the nature, benefit-to-harm and alternatives to urological treatment.

Note: I am aware that most urologists do not think of instillations of chemicals/intravesicals, or dilation of the urethra, and many other invasive treatments as “surgeries.” But these also have surgical CPT codes, they change and harm human tissue. This is discussed in this letter to three AUA Committees.

From 2009 to the present I have interviewed more than 3 dozen people who were diagnosed for and treated for IC/PBS, or what is now called “painful bladder syndrome (interstitial cystitis) and associated diseases.”<sup>liv</sup> These people are volunteers who responded to an e-mail I sent to all patient support groups in the United States, from an ICA list. Every patient’s story is unique, but there is a pattern also, a commonality. *First*, urological treatment does not work for patients, to say the least; the ICDB Study, the ICTTG and ICCRN trials,<sup>liv</sup> and our survey,<sup>liv</sup> [www.cystitispatientsurvey.com](http://www.cystitispatientsurvey.com) agree that patient symptoms are not improved by the treatment that the Practice Guidelines present. And *second*, contrary to what urologists say, that there is no known cause of IC/PBS symptoms, patient experience tells us that there are known medical causes and successful, noninvasive treatments which are not offered to patients. See point number 3 in this letter. I am just finishing a document about what 3 dozen patient interviews have revealed about what has actually improved patient symptoms and this document will be distributed to support groups soon; any urologist who wants a copy will be able to get one on our survey site within a month or two, and I hope some of you will expand this list and work to improve the diagnostic testing and treatments that patients have told us about.

The length of these stories is proportional to the number of surgeries patients suffer. James’ story is short because he didn’t feel right about a diagnosis that was a lifetime sentence, and the fourth urologist diagnosed him expeditiously, with pelvic floor dysfunction. PFD was causing his “IC/PBS symptoms.” James was referred for PFD physical therapy and this treatment, which is what he needed, helped him as soon as James embraced it. The other two stories are much longer. Susie’s story includes 4 years of treatment lines 2-5 in the Guidelines, 40+ surgeries, followed by diversion surgery and then more, unending surgeries for the “complications” of diversion surgery. It appears correct that diversion surgery is a failure for patients diagnosed with IC/PBS. The third story, Anne’s story, includes 16 years of more than 31 urological surgeries, all of them recommended by the Practice Guidelines. This is how one person experienced these surgeries – instillations of chemicals like DMSO, hydrodistention, implantation of two different Medtronic neurostimulator devices and 3 series of 20 Botox injections each, 2 series of Kenalog Steroid injections, again, lines of treatment 2-5 in the Guidelines. Finally, after 16 years of this, Anne got lucky. Information from her daughter’s roommate, in 2012, about myofascial stricture release physical therapy was what she had needed all along. The only ICCTG trial that urologists conducted which succeeded in improving patient symptoms is myofascial physical therapy. With myofascial release therapy, there has been a 75% improvement over symptoms that had been off the scale and getting worse with each new urological surgery. Anne’s description of Myofascial release physical therapy is very clear. There are severe allergies and severe pain



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from the antibiotics that accompany the urological surgeries for all patients; symptoms can be improved, but requires a lot of effort.

All three stories illustrate the grave importance of testing, during the Basic Assessment, for pelvic floor dysfunction (James), myofascial stricture and all the other medical causes of chronic urgency and frequency and pelvic pain (Susie and Anne); patients will tell you what these causes are, if you do follow up. All three stories also illustrate the havoc that ensues from the dozens of antibiotics that accompany multiple surgeries and from long term or “preventive” antibiotics, a routine urinalysis that isn’t sensitive enough, according to urological research<sup>liv</sup> as well as patients, and many other problems with the treatment. We now have the Human Microbiome Project. Microbiology, finally; microbiology has been moving in this direction since at least 1920, at Yale and other new microbiology departments.<sup>liv</sup> Somehow, everyone has gotten on the surgery train.

Urologists have long maintained that when patient symptoms worsen during the course of dozens of urological surgeries (Treatment Lines 2-6 of the Guidelines) that this is because of “progression of the disease.” However there is no evidence for this, and diversion surgery was called a failure in 1967 by Poole, the dean of urological surgery at that time, and in 2005, again, by Blaivas.<sup>liv</sup> In Susie’s and Anne’s stories, the drastic decrease in *quality of life* as the surgeries progress contradicts the self-serving “progression of the disease” opinion. And as far as I can tell, patients are not informed about the disagreement in the urological community.

Who gains from this? Certainly not Susie, who at 34 years of age lost her bladder, the length and health of her intestines, and much more, and certainly not Anne.

**All three of these stories** are examples of what it costs in months or years of pain, and what it costs financially, for two tier treatment – ineffectual, harmful urological surgeries followed by visits to doctor after doctor in different medical specialties, and health care providers such as physical therapists in a desperate search for relief. The cost for physical therapy is a fraction of the cost of multiple urological surgeries. Many patients can’t afford to look for the medical causes of their symptoms and get the treatment they need. This is also an unnecessary tragedy.

The devil is in the details. It has been my own and other patients’ stories that provided vivid and meaningful disclosure about urological treatment for IC/PBS and the alternatives.

Are not the 2011 Guideline recommendations and lack of disclosure not a breach of patient trust, Patients’ Rights, and also an abuse of power?

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**James’ story:** pelvic floor therapy for pelvic floor dysfunction, and a rapid recovery from “IC/PBS” symptoms.

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James was told by 3 Canadian urologists that he had IC/PBS. Three surgeries, that is instillations of chemicals, did not improve his symptoms. The lucky discovery of an apparently rare urologist who understands the role of pelvic floor dysfunction<sup>liv</sup> caused by trauma from sports, and the recommendation of physical therapy, eliminated his extremely painful “IC/PBS” symptoms with just a few sessions of therapy by a *skilled* physical therapist.

James’ story, in his words, 2011:

“If this helps someone, that will be my reward for telling my story.”

In 2008, all of a sudden I had terrible pelvic pain. I was away on a trip and also going thru a divorce. All of a sudden the pain came out of nowhere, after sexual intercourse. Maybe that was the trigger. Previously I’d had some frequency day and night. It came and went – I didn’t know why.

This was a disaster for me. I got seriously depressed. When I talked to patients I became more depressed. The problem is internal, they said – you’ll just have to live with it.

But basically the problem came from the pelvic floor. I didn’t even know what the “pelvis” is. Then all of a sudden there was this unbelievable pain.

I went to urologists. One of them did a cystoscopy and diagnosed me with IC. I wouldn’t allow the other two urologists to do more cystoscopy.

I started with Tylenol 3, then Percoset. I went back because I still had pain, and I had constipation. So the third urologist gave me a morphine patch.

I started to enquire about IC. I felt like my life was coming to an end. It was a shock to me.

I got these flares – now I see that some foods were triggers.

On the internet I found the IC Network and the IC diet, so I started the diet. That helped somewhat but still I had some discomfort.

So I started to look for a specialist. In Canada it would have taken 3 years to get an appointment with an expert in IC. I saw three urologists in Canada, and had about 20 instillations of a chemical – I don’t know which one. There was no improvement.

So I found two urologists in the United States. The first US urologist wanted \$3000. just to evaluate me. That didn’t seem right. But the I liked the approach of the secretary of the second urologist – she was kind and the price was reasonable. It wasn’t the money – I would pay anything to be healthy. But the kindness felt right.

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So I went with the second one. They wanted a medical history. One of the urologists in Canada told me I was wasting my time going to the US because the knowledge he had of IC was sufficient and no one could do more. He told me to take Uriset and I did this many times and it didn't help a bit. And he gave me a prescription for Elmiron. I didn't take it because I wanted a specialist first. I took the letter and went to the urologist in the US anyway.

In April of 2009 I saw this American urologist for the first time. He was very friendly. I was impressed with his manner and his thoroughness. He didn't do a cystoscopy. He said he didn't know if I had IC but he saw that I had pelvic floor dysfunction by just feeling my pelvic floor muscles – a finger in the anus, very simple, pelvic floor muscles that felt like a tight guitar string. Tight from my running exercise, most likely. He gave me an appointment for cystoscopy a month later.

With the cystoscopy he said he didn't see food sensitivity in my bladder – he suspected I didn't have IC. If I did it was mild. He repeated that my problem was tight pelvic floor muscles. He explained that some people have sensitivity in other parts of their body; I have it in the pelvic floor. He told me I had to do stretches, exercises, etc.- all those goodies.

Then back in Canada I told a patient support group leader<sup>liv</sup> about this and she told me she was having a group meeting with Carolyn Vandyken, a physical therapist.

I went to the meeting and Carolyn Vandyken said that often patients diagnosed with IC/PBS didn't really have that problem - they had tight pelvic floor muscles. She said, "If you fix the pelvis you'll get rid of the symptoms called "IC."

I started the therapy. But I wasn't dedicated and went back to my old life; I introduced more foods, careful not to be extreme because of the terrible flares food had caused in the past. The symptoms were very painful.

I also started exercise. I tried running again and noticed discomfort and frequency of urination after sex- for a few hours. Apparently running wasn't the right exercise for my condition.

So I went to see the urologist in the US two more times. On the third visit, I was upset because the pain was coming back. He told me my pelvic floor was definitely tight and I needed to go back for therapy – stretches etc.. He gave me the book Headache In The Pelvis.<sup>liv</sup> I was willing to go to California. But the urologist said I could do the therapy in Canada.

I stopped running. I did the stretches, swimming and the elliptical machine. I also did hot whirlpool, without the jets. After about 2 months of this, my pelvic floor tone was back to normal and the frequency disappeared. I could sleep better. Then I introduced more foods and I felt fine!

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This urologist in the US was a savior for me. He nailed the problem. He was the only one. Three urologists in Canada never mentioned pelvic floor issues. I don't think they knew anything about it – they didn't check me for that – it's simple to diagnose.

The urologist in New York didn't have that attitude – he's a real doctor, there to help you. He is a good hearted man. He explained, and he diagnosed me correctly. He didn't promise 100% but he said I'd get much better. He was right. His office even did follow up – they called me to see how I was doing! One time I had a problem and called and they gave me a prescription.

My best advice is to find a specialist like this urologist. I listened carefully to what the other 4 urologists said, and I had a gut feeling that they were not right. My gut feeling about the urologist who diagnosed me correctly was that he understood what the problem was.

And of course, once you have the right diagnosis, find the right pelvic floor therapist. Carolyn Vandyken and the pelvic floor therapist closer to home, who treated me, saved me from a lifetime of terrible pain.

“If this helps someone, that will be my reward for telling my story.”

**Susie's story** came to me via Jill Osborne's site, the Interstitial Cystitis Network. Jill helped me to post a request on her site asking people who had experienced diversion surgery if they would be willing to be interviewed about that experience. Three people responded and I interviewed them; one of them is Susie. Her story is representative.

**Part One of Susie's story, a summary:**

- Susie had more than 42 urological surgeries and more than 40 courses of antibiotics
- *Quality of life* before and following these surgeries drastically deteriorates.

**Part Two of Susie's story, a summary:**

- Three major diversion surgeries followed by 40 hospitalizations for kidney infections and bowel blockages, and many more surgeries for other “complications” of diversion surgeries and antibiotics, including rupture of tendons in hands and feet.
- *Quality of life* during and after these surgeries becomes much, much worse than when all this “treatment” began. Here are the details that are missing from the urological literature.

**Part One of Susie's story; the patient experience of urological surgeries and antibiotics**

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I, Kay Zakariassen do not give medical advice or engage in the practice of medicine. Kay Zakariassen under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

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- **1984-85** – Before urological treatment, Susie had chronic urgency and frequency, but she was coping nicely.

*Susie's quality of life* was not perfect, but it was infinitely better than any point in the process of her urological “treatment.”

- **In 1986**, Susie's urological diagnosis and treatment begins with 2 surgeries: a cystoscopy and hydrodistention.

*Susie's quality of life* after the hydrodistention added extreme pain to the symptoms before treatment began, urgency and frequency.

Most important, it appears, was the diagnosis of IC/PBS; “He (the urologist) told me I had mast cells in the bladder and a lot of bleeding and that I did have IC.”

This diagnosis started the whole cascade of surgeries and the deterioration of *quality of life* I have seen in patient interviews and in our survey, which asked patients whether their symptoms were improved, worsened or not effected by the various “options” they experienced, [www.cystitispatientsurvey.com](http://www.cystitispatientsurvey.com).<sup>liv</sup> The letter discusses the harm from these surgeries. I am aware that this is speculation, but as I read about hydrodistention, and glomerulations, I noticed that at least two urologists in the literature describe seeing no glomerulations with the first hydrodistention, and many with the second.<sup>liv</sup> What does this mean; is there sequence or causality here? In any case, the very invasive, diagnostic surgery, which causes bleeding in the bladder, hydrodistention, was the beginning of Susie's extreme pain.

- **In 1987**, Susie's urological treatment would include 15 surgeries (instillations of DMSO, Gynecological D&C and laparoscopy, hydrodistention and cystoscopy, and YAG laser treatment)<sup>liv</sup> and more than 19 courses of antibiotics, prescribed for 4 bladder infections and to accompany the surgeries. All of these surgeries were again recommended in the 2011 AUA Practice Guidelines for treatment of IC/PBS.

*Susie's quality of life* at this point had severely deteriorated:

Urgency and frequency continues after all the surgeries in 1987

Extreme pain continues, and worsens.

There were 4 bladder infections; infections had not been a problem for Susie before these urological surgeries began. Instrumentations can and do cause infection and even biofilms, which are very hard, almost impossible to detect and treat; Susie has ongoing bladder infections during all the bladder surgeries

Constant bladder spasm – Urispaz is prescribed but does not give relief

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- **In 1988** Susie was subjected to 23 surgeries (multiple instillations of DMSO, Solucort and heparin, 4 “irrigations” (Susie can’t read the substance in her records) second Yag laser, third hydrodistention and 2 spinal taps, and at least 24 courses of antibiotics,<sup>liv</sup> including at least 2 broad spectrum antibiotics in 1988. (Neuroxin and Cipro)

I urge you to read the long list of surgeries and dates of service provided in the footnotes.

***Susie’s quality of life***, following these surgeries and antibiotics was:

Continuing urgency and frequency

Continuing bladder spasms – urispaz continues

Far worse pain – Susie is now on oral Darvocet & topical Tetracaine<sup>liv</sup> “There was a lot more pain,” Susie says.

Serious loss of capacity of the bladder – about 125 cc when under anesthetic, which brings worsening urgency and frequency and pain

In April of 1988, Susie was referred to a urological surgeon for consideration of diversion surgery, and at about 32 years old, she is faced with the possibility of losing her bladder altogether. This is less than 2 years into urological surgeries.

Since there was little or no disclosure about what her *quality of life* would be before any of these 40+ preliminary surgeries, let alone what it would be like after diversion, she was making this crucial decision alone and in the dark. Most important, Susie was not, in the beginning, tested for any of the medical causes of her initial urgency and frequency (e.g. allergies,<sup>liv</sup> infection not revealed on a routine urinalysis, pelvic floor dysfunction, and others), nor were there any alternatives offered – only more urological surgeries. and worsening alternative causes tested for diagnoses or treatments were offered at any stage of treatment, from 1986 to 1990 when she agreed to have her bladder removed. It is a specialty of specialized medicine to ignore medical specialties that are not your own.

Susie: “I don’t know if the DMSO caused all this but I did get much worse after these treatments.”

This author asks: Would the urologists who treated Susie have recommended these surgeries for themselves, or for their daughter, their wife, their husband or son?

- **1989:**

Susie: “In 1989 I saw a second urologist.”

There followed one Surgery, a hydrodistention (or 2, if instillation was added) and at least one prescription for antibiotics.

The hydrodistention was severe: “... a hydrodistention of my bladder was done that was much more severe than the normal one, despite the fact that the urologist who had been consulted in 1988 warned against any more hydrodistentions, because that could cause more problems.”<sup>liv</sup>

***Susie’s Quality of life: at the end of 1989:***



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All of the problems Susie had in 1988 were the same in 1989, except that another hydrodistention was done in 1989, contrary to the warning of a consulting urologist. “The hydrodistention was horrible; it was supposed to be same day surgery but when I was in recovery there was so much blood that they had to admit me to the hospital. I don’t know why it was so bad but it was and the pain was horrible. And there was no benefit from it. I was in this pain, which was even worse than before, for a couple of months.”

Chronic urgency and frequency continue

Bladder spasm continues – urispaz continues

Far worse pain – patient is now on oral Darvocet & topical Tetracaine<sup>liv</sup> “There was a lot more pain,” Susie says.

More antibiotics, more iatrogenic disease I think it’s fair to assume that after 40+ courses of antibiotics, Susie has some of the iatrogenic diseases caused by antibiotics, including a *Candida albicans* infection and allergies. Solucort indicates severe allergies and medical conditions.<sup>liv</sup>

Serious loss of capacity of the bladder – about 125 cc when under anesthetic – , which brings worsening urgency and frequency and pain

According to urologists, her only option now was diversion surgery:

Following all these surgeries, Susie’s urologist said that “the bladder had gotten so bad that I needed surgery – diversion of the urine. This meant having my bladder removed. I was just in my early thirties.”

Next, says Susie, I went to a famous urologist in NY, about the question of having my bladder out. His wife was a social worker and asked me to keep a journal. I thought that was crazy because they thought I could retrain the bladder and I had absolutely no control – so I did not continue with this doctor.

Again, there were no other alternative testing or treatment, outside urology, offered to Susie, by any doctor.

**Part Two of Susie’s story:** 1990-2009; 3 major diversion surgeries followed by 40 hospitalizations, many more surgeries; the patient’s experience of the “failure” of diversion surgery

At 34 years of age, Susie was told that the only thing urologists had left to offer her was diversion surgery. There was severe and chronic pain every day. Susie was faced with an impossible decision, having almost no information about any of the urological treatment, including diversion surgery, which she was legally entitled to by Patients’ Rights. I asked Susie if any of the urologists had asked her if she had allergies or any other condition before all these surgeries began; if allergies might have been a cause of the initial urgency and frequency. “It never came up,” Susie replied. Allergists had identified urgency and frequency with food and other allergies decades before this.<sup>liv</sup> There had even been at least one lecture about this at a urological annual meeting in 1971.<sup>liv</sup> Why has there been half a century of delay in considering that some diseases – like allergies – might be a clue to understanding chronic urgency and

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frequency and urgency and pelvic pain? Why are American doctors so blind to the alternative diagnoses and treatments offered by other medical specialties, and care givers like physical therapists? In France, physical therapy pre and post childbirth and pelvic surgery has been routine for a long time.<sup>liv</sup> One young urologist told me, on film, that he has to do *something* for the patient – and to him, dilation of the urethra, which he calls “voodoo,” seems “safe,” and it’s the “mainstay of the private practice.”

The Guidelines call diversion surgery treatment line number six. Are these multiple surgeries and the “final treatment,” diversion surgery, not an assault of patients?

**Three diversion surgeries;** I ask you to imagine not only the physical ordeal for this patient, but the social issues, the emotional issues.

1. **The first urinary diversion operation:** “My bladder was disconnected from the ureters but left in my abdomen, that is, not taken out. The ureters were then implanted into a pouch constructed of intestine, a substitute bladder. The intestinal pouch was then surgically attached to the inside of my abdomen, below the belly button, and a “stoma” or hole was created between the intestinal pouch and the outside of my abdomen.

***Susie’s Quality of life:***

“Every day I would have to catheterize the urine many times.”

“This didn’t work. At first all the bladder symptoms disappeared – there was no more pain or frequency and urgency, or pain in the new substitute bladder, the intestinal pouch created inside my abdomen. The doctor thought the pain had disappeared because my urine was toxic and had caused the pain in my real bladder.

“But then the terrible symptoms I’d had before the diversion came back - terrible pain in the pouch and terrible frequency and urgency. The “stoma” and the pouch started to spasm so badly that urine shot across my hospital room to the wall. I had to try the medicine they use in surgery, heparin; I had to inject it thru the catheter. It didn’t stop the spasms, which is what it was supposed to do.

“The spasms were extremely painful and there were also many infections and many more antibiotics.

2. “On May 1 of 1990 there was stricture of the stoma – it closed up or narrowed so much that I couldn’t get a catheter in to drain the pouch. The second major surgery was about fixing this.

***Quality of life:*** One of the complications from the first diversion surgery was a severe hernia. They had to move the loop and also move the stoma to the other side of my

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abdomen. I don't remember why. I think it was because the hernia was so bad that the abdominal wall wasn't strong enough to hold the stoma anymore so they had to move it to the other side.

A "regular" diversion surgery was done at this point, creating a pouch to hold urine outside the body as well as the one inside the bladder. A lot of my intestine was used to provide the internal pouches.

3. "The third major surgery was because the intestinal pouch, the substitute bladder, ruptured – it broke. Actually, I'm not sure if it was the second or third substitute bladder that ruptured. But it was unbearably painful.

### ***Susie's Quality of life:***

"I was in and out of the hospital too many times to count in 1990, all for problems caused by the first continent diversion. They had to open up my abdomen for many reasons, and things were so complicated, so painful and so frequent that I am not even sure anymore what all the things were that happened. It was such a mess, so horrible.

"I was always on the same floor – the urology floor – because these were all urological surgeries.

"Sometimes the general surgeon was called in and he worked with the urologist; they operated together to try to correct complications from so many surgeries – hernias and strangulated hernias, and other things. Three times the general surgeon was called in to help deal with these complications of so much surgery. I had two hernias, I think.

"There were spasms of both the internal and external pouches. One of the tests was to drink all this stuff. They had me come in and they gave me an IV that starts the kidneys going, I think with a chemical called Lasix.<sup>liv</sup> Spasms would cause urine to shoot all the way across the room. Other times I'd be lying flat and it would shoot up like a fountain. Nurses would try to put a catheter in, but spasms were so bad that they couldn't get the catheter in or out.

"There was just one bad thing after the other.

"At one point Total Parenteral Nutrition (TPN) was started, total nutrition through a main line.

"Then one lung collapsed, and they had to put in a chest tube for a couple of days and check the lung with x-rays to see if the lung was recovering. The chest tube was defective and they had to do it again.

"This and all the other procedures were too painful to describe – unbearable pain.

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“Surgery is horrible – there were lots of things that were side effects of too much surgery. “There was so much scar tissue in the intestines that a colonoscopy would only go ¼ of the way into the intestine.

Throwing up feces – intestinal content: “One of the intestinal hernias was so bad that it looked like a breast on the outside of my stomach. The intestines had not just herniated but wrapped around each other – you can die from this. The doctor had to call the general surgeon in to work on this.

“The intestines don’t work because of complications from numerous surgeries. I have gotten such horrible constipation, more than once, for two weeks, that I started to throw up feces; this happened last year and then again this year – Doctors say this is because of scar tissue caused by operations...

“I used to have bad bloating. It’s not as bad now.

“If the doctor takes the bag off and looks thru the stoma, through the loop of intestines that serves as diversion to the outside bag, the substitute bladder, there is “cobblestoning,” this isn’t healthy.

“They had to put in nephrostomy tubes. The ureters had narrowed causing kidney infections.

“One day, a Saturday, I felt sick. A friend was coming and we went antiquing. Halfway thru the trip she had to take over the driving, and when we got to the friend’s house, I couldn’t sit up. I was throwing up, and had a fever of 104. An ambulance was called to take me to a major teaching hospital, from the local hospital. This was a trip of more than an hour. When I got there my temperature was 105 and I was in the hospital for days. A month before this there had been a Kidney infection. My doctor decided to find out what was causing these infections and the previous ones. He put in a nephrostomy tube to expand the ureters. These tubes were inserted into my side, and out thru the stoma into the bag. Interventional radiology was done to measure the pressure - but it didn’t work. Major surgery had to be done to fix the ureters. I think there was a hernia too.

“In 1996 or 97, I started getting horrible blood in the bag – mostly blood. I don’t know the reason for that, but they had to do surgery for that. I don’t remember why.

“I had a few stoma hernias. In the area around the stoma, the muscles are cut, it’s weak, and twice I had very bad hernias.

People should know that with all the complications and infections I had a lot of Cipro and I’ve gotten **tendon ruptures from Cipro**. They don’t give Cipro to children now because of this; there have been a lot of law suits. My Achilles tendon ruptured, the

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tendon in my thumb also ruptured. They had to replace the tendon in my thumb with a tendon from the finger next to it. The big toe in my foot ruptured. You have to be really careful with Cipro.

“I had Botox about the beginning of 2007. He would inject Botox right around the stoma, into the abdominal wall, to stop the spasms, but it didn’t work. There were spasms of both internal and external pouches. He sent me to a plastic surgeon and he cut my nerves to the abdominal wall and that lessened the spasms. I still get spasms, but less severe.

“Things have calmed down now, in a sense. I haven’t had a major urological surgery since 2003.

“In the late 1990s or early 2000 I had stricture from the diversion, with horrible pain. My urologist at the same teaching hospital sent me to a pediatric urological surgeon because they do more repair of stricture and he found that the loop, before it comes outside, had stricture and the urine was backing up; he had to go in and open it up.

“Twenty years of complications - my urologist feels horrible because he didn’t put an external pouch in, in the beginning.

I list the following because who knows where these tumors and neurofibrosarcoma came from. Has the human body evolved to cope with all the poisons we throw at it from pharmaceuticals, surgeries, let alone all the other environmental toxins? It seems to me that we don’t really believe in evolution, or we would be a million times more careful about medical care now, given the constant “Silent Spring” that assaults our bodies daily.<sup>liv</sup>

Susie continues: “I also had other major surgeries that as far as I know had nothing to do with the urological problems. And I had a spinal tumor. I had operations for these conditions because I would have been paralyzed if I didn’t have the surgeries.

“I also had Schwannoma, or nerve sheath tumors, neurofibrosarcoma, in my foot.<sup>liv</sup> I was told I’d have another tumor in about 10 years.

“This year I was at a pain clinic at the same teaching hospital, and a man there said that his wife was given an antibiotic and it saved her life... I thought, I went through all these surgeries and another woman was saved by an antibiotic?

“I asked my urologist about this and he said if an antibiotic cured her she didn’t have IC.

“No one needs to go through what I went through.”

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In an e-mail I had today from Susie, she says “I wish someone would have talked to me before this journey had started.”

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## **Anne’s story:**

An overview:

“From 1997 when I was diagnosed with IC/PBS and treated with more than 31 surgeries, until 2012, I felt like I was constantly holding a scream in.”

What finally did work for Anne, in 2012-2013 was the subject of a urological trial between 2000 and 2010, the only trial of many ICCTG and ICCRN trials that was successful, that is myofascial physical therapy. This treatment has relieved 75% of Anne’s pain. In Anne’s book, this is nothing short of a miracle, and she is giddy with happiness. Her description of myofascial release therapy, is very clear and helpful, as only a patient’s point of view can be.

Anne’s story involves a history of over prescription of antibiotics from the age of 13, for acne, for multiple urinary tract infections (4-6 times a year, from age 16 to 26, even though the cultures were negative), for major pelvic surgeries, and more antibiotics to accompany multiple urological surgeries, from 1997 until 2012. Forty-four years of almost constant antibiotics. “Five of these years I took Keflex,<sup>liv</sup> 500 mg, 3 times a day,” says Anne. (One wonders if drugs like Keflex, which can cause rash,itching,hives,etc., can cause these symptoms in the bladder, and actually cause chronic urgency and frequency.) From the age of 16 until about 26, I was prescribed antibiotics 4-6 times a year for bladder infections, even though the urinalyses were all negative. All these antibiotics caused a Candida albicans infection, in both the intestine and vagina, and then there were multiple prescriptions for Diflucan. The Candida infection also caused multiple allergies to foods, and an anaphylactic allergy to latex. “I rarely eat out because latex gloves are often used by restaurant workers and my throat begins to close up with the first bite. There are a lot of foods I can’t eat. My mother and I had no idea that the consequences of ongoing antibiotics would be a lifetime of Candida albicans infection, and all the problems that go with that.”

Anne’s history also included six pelvic surgeries, the sixth a hysterectomy. In 1997, after a hysterectomy, Anne was diagnosed by a urologist with IC/PBS.

Anne says, “What urologists sold me was hope. I agreed to urological treatment, which was extremely painful and invasive, because I was desperate. I couldn’t believe that these symptoms were my life sentence. So I did what urologists advised. But when the symptoms began, the



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urgency and frequency was at about 5 on a scale of 10, and the pain in my abdomen, which seemed to be coming from the bladder, was at about 8. After multiple surgeries, my symptoms were at 10 on a scale of one to 10.

Anne was not informed of the nature of the treatment, the benefit-to-harm ratio, or of any alternatives outside of the treatment urologists offer. Anne saw 16 doctors from various specialties during the 16 years of urological surgeries. None took a history of her antibiotic use, nor gave her realistic disclosure. The alternatives to the urological diagnosis and treatment were not given. Successful treatment would come in 2012, from a discussion with Anne's daughter's roommate and the roommate's mother, about myofascial release therapy.

“In 1978, when I was 25 years old, a series of major surgeries began. These surgeries required even more antibiotics. The surgeries were explained by the doctors involved in the following way:

- “First there was a back surgery; a broken vertebrae from a misstep during a Christmas tree hunt.
- “Then there were 6 pelvic surgeries:
  - In 1985 my left ovary was removed: “The gynecologist told me that this ovary was enveloped by a cyst, which was strangling the ovary, and the cyst could not be peeled off of the ovary – the ovary had to go. They said they knew there was a cyst because intercourse was painful and diaphragm popped out.
  - During the ovariectomy, the removal of the ovary, an appendectomy was done “because the appendix appeared to be inflamed. The appendectomy was done without my permission. They tell you before the operation that ‘If there’s anything else that is wrong when we go in, we’ll fix it.’
  - Third, there was a gall bladder attack, and a removal of the Gall stones, in 1994.
  - Fourth was an exploratory laparoscopy. They were looking for PID.
  - Fifth, was another exploratory laparoscopy. This might have been the beginning of myofascial symptoms – I felt like I had octopus tentacles in my abdomen. They were probably trying to find an explanation that they could give you a pill or a surgery for...
  - Finally, there was a hysterectomy, in 1996, to stop chronic bleeding.

“After the birth of my second child, in 1991, the chronic bleeding caused anemia. The gynecologist claimed that my one remaining ovary was not responding to a normal cycle. I was exhausted all the time. The gynecologist told me, ‘You don’t have to live like this, you can get your life back.’ That was his promise. So, to stop the bleeding, I agreed to a hysterectomy, which was performed in 1996, with removal of both uterus and right ovary. The hysterectomy felt liberating for a short period of time, because I was no longer bleeding, but I traded one nightmare (bleeding and anemia) for another – chronic urgency and frequency and pelvic pain – what the urologists told me was IC/PBS.

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“It is questionable whether I needed any of these surgeries, except the back surgery. What I got out of them was chronic symptoms of urgency and frequency and pelvic pain, what urologists call IC/PBS.

“After the hysterectomy, suddenly, on May 12, 1997, I had chronic urgency and frequency and chronic pelvic pain. My symptoms were a 5 on a scale of 1-10 for urgency and frequency, and 8 for pelvic pain. My life had become a living hell.

“I felt then like I had a birthday candle that’s lit, which is shoved up my urethra and is burning in my bladder. I felt this way from the beginning, in 1997, until the end of 2012. I was 42 years old.

“I remember when these IC symptoms began. We were moving and I was reaching for a box. I felt like I’d torn something in the lower abdomen – there was an incredibly sharp pain, I was doubled over, and there was also burning. I also felt like I had a severe UTI, but all urinalysis was negative.

Anne had in fact torn something – myofascial tissue. Perhaps other patients have too. The urological literature reads: “The acute to subacute onset (of symptoms) is remarkable for what proves to be a chronic disease. Many patients can remember the day their symptoms began!”<sup>liv</sup>

“In addition to the IC symptoms, I realized I had developed an anaphylactic allergy to latex. I first had this reaction while eating at a restaurant. I began to turn blue.

“I saw an allergist and he said he was surprised I hadn’t died on the operating table in reaction to the latex surgical gloves. I don’t go to restaurants much anymore because if the staff uses latex gloves my throat starts to close up with the first bite.

“I believe that the antibiotics, the hysterectomy and the allergy to latex caused my IC symptoms – chronic frequency and urgency and chronic pelvic pain. I was never told that a hysterectomy could cause these symptoms, and yet, I think that’s what happened.”<sup>liv</sup>

### **The diagnosis of IC/PBS was in 1997.**

- The first health care provider I saw after the IC symptoms began, in 1997, was a nurse practitioner. “She gave me an antibiotic. And she recommended Diflucan to counteract the antibiotic. I took pyridium – I thought I’d be ok in 2 days. I was not ok.
- “About this time I started doing my own research. Someone said to me, perhaps the nurse practitioner, that my symptoms sounded like I had a Candida albicans infection. I didn’t know what that was. The nurse told me about a book called The Yeast Connection and the Woman.<sup>liv</sup> That book explained why I had so many yeast infections,

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and allergies to latex and food – it was a *Candida albicans* infection from so many antibiotics, and this was causing both the yeast infections and the allergies to latex and food.

“There was also a chapter on interstitial cystitis in the same book, which jumped out at me. The symptoms described by this author were the symptoms I had – urgency and frequency and pain in my bladder. From then on I was convinced that I had IC and I was desperate to be tested for it, and treated.

- “The second practitioner I saw, also in 1997, was a Naturopath,” Anne says. “The book The Yeast Connection and the Woman, and the Naturopath, recommended that I start the Candida diet, a diet to help control the Candida infection (a fungus) and the symptoms I had. Since Candida thrive on sugar, wheat, dairy, fruit, gluten, I had to quit eating all those things. I only ate apples, pears, blueberries etc. It helped a little. But I was still utterly miserable.
- “The third health care provider I saw, in 1997, was the first of many urologists. Because my husband and I were moving from Santa Fe in 2 weeks, this urologist referred me to another urologist, in Denver, our destination.
- “I told the urologist in Denver that I thought I had IC/PBS. I told him, ‘I just moved, I’ve got kids, I need help!’
- “This urologist convinced me that my urethra was too small (25F) and that I wasn’t getting a normal urine flow.  
“The urethral dilation was in the office. He said all I needed was a dilation of the urethra and I’d be fine. I wanted some kind of pain killer before he did it. I had so much pain that I couldn’t even handle a pelvic exam. But he didn’t want to give me a painkiller for my symptoms or for the dilation either. He told me, ‘You need patience, you may get worse before you get better...’ ‘you’re going to get worse or better.’  
“He used the French 7 dilator. I’ll never forget that. He shoved the dilator up my urethra a few times, and I produced these guttural sounds that I’d never heard before, from the pain. I was begging him to stop. I felt like I was being raped.



These are the urethral dilators.<sup>liv</sup>

“After the dilation of my urethra,” Anne said, “My husband had to come and get me. I went to bed and I was in shock for days. This urologist suggested that I have more dilations! I was not helped by the dilation because a narrow urethra was not my problem.

“This was when I realized I had to become my own health care advocate; I realized that I had the power to make the decisions about what I should agree to, instead of taking doctors’ views at face value. I asked a lot of questions of urologists after that. Still, the pain was so awful, and the doctors were so convincing, and I agreed to more.

“Finally, I told this urologist about the book I’d read, The Yeast Connection And The Woman. I told him that I thought I had the IC/PBS that was described in the book, and I wanted a hydrodistention under general anesthesia because the book said this was needed for a diagnosis. He said, ‘You don’t want IC – there is no cure.’ He didn’t want to do a hydrodistention. But I insisted because I was sure I had it and was desperate to get treatment for it.

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“The hydrodistention was done in the hospital, along with a biopsy, and when he saw me afterwards he said, ‘I was wrong. You have one of the worst cases of IC I’ve ever seen.’ He handed me the IC diet sheet, a 30 day prescription for Tylenol with codeine, and he said ‘I don’t treat IC. Good luck.’

“A doctor who is a friend told me that he got a 15 minute lecture on IC in medical school. He was told that IC patients are middle aged women who were looking for drugs and complaining about womanly problems. He was told that IC is a psychosomatic illness, and to give patients a one month prescription for pain and get them out of the office.

“The urologist who did the first hydrodistention did this to the letter.

- “In 1998-99 I saw a uro-gynecologist,” Anne says. “She told me that she treated IC.

*There followed at least 12 surgeries: a second hydrodistention, a second biopsy, 10 instillations of DMSO (she wanted to do dozens), and several instillations of Heparin and Lidocain; this is a patient’s view of what this felt like.*

“The urogynecologist wanted to do her own hydrodistention and biopsy. This was my second hydrodistention and my second biopsy. She said, ‘I see where the first biopsy was done during the first hydrodistention, and it looks as raw as if you’d just had it done.’ Wouldn’t you think this physician would have thought twice about doing a second one when she saw the damage the first biopsy had done, and that it still hadn’t healed? No. She did a second biopsy.”

Anne’s assessment of hydrodistentions is: “What these hydrodistentions did do was make me feel sicker than I did before I agreed to have them done. I likened them to chemotherapy treatments – all of the bad side effects with no therapeutic results. For example, bleeding. Nobody told me about the bleeding from hydrodistentions. I thought they had punctured something. I was sold a bill of goods regarding hydrodistention. It was necessary and good for me said my urologist. ‘All my patients feel better and have relief from pain for several months. Many women routinely have hydrodistentions every couple of months because it stretches out the bladder and you can hold urine longer.’

“I will never have another hydrodistention again,” Anne thought at the time. “There has to be a kinder, gentler, better way to diagnose and treat IC than by using hydrodistentions.”

But there would be more, because Anne was desperate, and because of the promises that urologists, a urogynecologist and a gynecologist had made, that the hydrodistentions would help. “In general they told me that we’d just have to keep trying several ‘options,’ and eventually we’d find something that would help me. Every patient is different, they said. We have to find out what works for you.

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“Then, the urogynecologist told me that I needed instillations of DMSO; her plan was to do it once a week for a year. I had 10 instillations of DMSO, one a week for 10 weeks, and then I refused more.

“I lost 15 pounds due to severe vomiting and diarrhea. I told the urogynecologist this and she said that my experience was par for the course; ‘DMSO takes out the toxins,’ she said. ‘There are obviously a lot of toxins in your system – you have to give it time to work.’

“Frankly, it was hard to tell the difference between hydrodistentions and instillations of DMSO. I was expected to hold the DMSO for up to an hour. It was extremely painful. I guess the difference is the time and the volume of chemical or water that is put in the bladder.

“I can’t believe I believed everything the doctors told me,” said Anne. “DMSO makes you reek of garlic. My husband couldn’t sleep with me – I slept in the guest room. Once I was standing in a horse barn waiting for my daughter to saddle up and someone said ‘Who rubbed a horse down with DMSO?’ They use DMSO for joint pain and inflammation, on horses. I was mortified. I finally spoke up and said, ‘It’s me – I’m the one who smells like DMSO.’ She asked me why, and when I told her about the instillations she was shocked – she had never heard of anyone using it internally.

“I could barely stand up. The year that I had DMSO instillations was the year I lost fifteen pounds. I called it the DMSO diet. I really didn’t have fifteen pounds to lose and I looked like I had been through chemo.

“But I had a 6 year old who I was trying to be a mother to and I had to keep it together until I got home.

“My pain level was still ten on a scale of one to 10. The Lidocaine and heparin didn’t help at all. I was desperate. Pain. My closest companion. I didn’t think I could be in more pain, but I was.

- “In 1998 and 1999 I saw a compassionate internist. I showed him my medical records, and he agreed to manage the pain. The urogynecologist didn’t want to prescribe pain medications. By this time I had 2 young children, and I couldn’t be a good mother with all that pain. My son says he doesn’t remember any time I wasn’t a good mother – ‘meals, practices, etc....what else could you have done to be a good mother?’ But I felt like there was a fog curtain between me and the rest of the world, including my children. The internist was a very kind man. He just wanted to make me comfortable.

“I took non-narcotics during the day - anti-depressants - Elavil, and other things, because they didn’t make me so groggy. These drugs helped me to function during the day.

“And I took the prescription narcotics at night. The drug schedule revolved around rest and helping the kids and family – managing while taking these meds, pretending to be ok. I was so overmedicated – I can’t believe they gave me that much stuff. The pain so severe that I couldn’t



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have functioned without it. But I was still driving with the narcotics in my system. I was careful about when I picked the kids up, watchful of the level of medication, but when I moved here from Denver, a pharmacist told me I should be arrested for driving with these meds in my system. I was a menace and a danger with four or five things in my system at a time. I took the narcotics only very sparingly in the daytime, mostly Percocet, along with Elavil and Peridium, on and off. The drugs lowered my pain level from 10 to 7-8. Pain killers take the edge off, but they don't begin to stop the pain. The side effects of the narcotics were horrible constipation, foggy, dopey brain, memory problems. My emotions were on edge because of the pain; I felt like I was constantly holding a scream in. That's where I'm still at, pain at 7-8 every day," Anne told me in 2010. I also have urgency and frequency – the urge to urinate is so strong that I go to the bathroom 40-50 times a day. I started staying at home most of the time – from 1997 on. I didn't leave the house a lot. And I dreaded the term 'bladder cripple.'

- “We moved again in 2001, this time to California, and I had to find a whole new set of doctors. A new urologist, my fourth, said there was nothing more he could do. The plan was that I would see him every 3 months, a requirement of the pain manager. It's a game you have to play to make everybody happy. The urologist would check my urine and I'd pay him \$100.

- “Because the pain was so severe, despite the drugs, I went to see a fifth urologist, at the University of California, Los Angeles. He did his own hydrodistention. He was famous; he suggested an implantation of a neurostimulator device. However, he had only done 4 implantations – I would be his fifth. So I sought out a doctor who had more experience.

- “This doctor was at UCLA. I'm not sure if he was a urologist or an internist/pain manager. He required his own hydrodistention also, to verify IC! A psychological assessment was also required, to make sure I could handle the implant process. I passed the assessment with flying colors. You have to sign a paper saying you won't do anything like go on a roller coaster, ride a horse, or do anything else which might unseat the device.

“First, there was a trial of the device. A slit was made in the skin, so that an electrode with a small wire could be threaded to the nerves. The main part of the device was outside the body. I felt some relief, so I opted for implantation of a neurostimulator device, yet another surgery.

“The neurostimulator looks like a pacemaker and they put it at the upper portion of my right buttocks, with wires threaded to the bladder area and nerve endings there. There's a tapping sensation from the neurostimulator, at the nerve endings, and the device supposedly intercepts the messages of pain and frequency. At first you say to yourself that you have to get used to it and you adjust the frequency of the tapping, with a remote control which you lay near the implanted device. Then data is entered. You can't change this original setting – only the doctor or the Medtronic representative can do that. And neither the Medtronic representative nor the doctor are allowed to claim that the neurostimulator will relieve pain - they are not allowed to say 'pain.' They are supposed to advertise less 'frequency.' The federal Food and Drug Administration, FDA, has approved the implantation of the neurostimulator only for frequency and urgency.

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“The neurostimulator gave no relief from urgency and frequency or from pain. There were continual readjustments of the programs. The doctor or representative would say ‘turn it off for 3 weeks, then reboot the computer.’ At this point we all agreed that the neurostim was a failure. Then the representative from Medtronics said I should wait until the battery died.

“In the beginning you want it to work so badly that you convince yourself that it’s working. But I kept up pain management medications, because I wasn’t getting any relief from the neurostimulator.

“After a couple of months you see it’s not working – and there was this incessant tapping that drove me insane, and there was still pain. Finally there was the realization that ‘holy shit – what have I done!’

- “At this point I went back to the doctor in Arizona and asked him to take out the neurostimulator that he had implanted. It had been in for 4 years by then.

- In 2005 Anne and her husband moved to Arizona. With the move to Arizona I had to find all new doctors - pain manager, urologist etc. and pharmaceutical pain medication was continued.

- “Still desperate, in November of 2008, I flew to Denver, to see a neurologist who was working closely with my first pain management specialist. He specializes in chronic back pain, and he thought I was a candidate for a second neurostimulator, which had 4 electrodes instead of 2, a different Medtronic device, the ANS device. This time they had to remove bone at the base of the spine in order to make room for the electrodes attached to the wires of the device.

“In February of 2009, this second stimulator, ANS device, was implanted. With my pain and frequency at an unbearable level, 7-8, even with pharmaceutical narcotics, I was beyond desperate. And with these symptoms, and the medication, I was operating in a dense fog.

“But the second Medtronic device didn’t work either. I kept turning the device on and off, and hoping that with reboot I’d get a little relief,” Anne told me.

“A year later, in 2010,” Anne said, “I haven’t found the courage to admit that I have to have it taken out. Admitting that it didn’t work the second time was very hard. It was an expensive surgery. And I have a huge gash – a 4 inch diagonal scar – where they slipped the device into a pocket of fat at the top of the buttocks. When you sit down, you feel it. Also, there are two small incisions at the base of my spine, required to get the wires to the bladder. Unfortunately, the two electrodes at the base of my spine were enmeshed in muscle and couldn’t be removed. I’m tired, discouraged, despondent. I keep turning the device on and off, and hoping that with reboot I’ll get a little relief,” Anne told me.

- “Shortly before the second neurostimulator was removed,” Anne told me, in 2010, “I went to see a urologist whose book I had read. It took 6 months to get an appointment. Finally, while I waited to see him, 3 women slammed out of his office, throwing their pocketbooks down, etc.. My father said, ‘Let’s leave.’ But I had read the urologist’s book on IC. He seemed to understand the disease and I wanted to know what he thought. I too left his office in disgust.

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Some days it's just so bad I'd almost rather not live anymore. When someone gives you a glimmer of hope, you do it. I still urinated 50 times a day. No sleep.

In e-mail shorthand, Anne told me, "I am so classically ic it's scary. chronic uti's as a teen, followed by chronic bladder infections and pelvic inflammatory disease followed by lots of gyno problems ending in a complete hysterectomy followed by the onset of ic at age 42.

And in an e-mail in July of 2010, Anne wrote to me about trying to carry on, despite everything. Life has very difficult, painful jobs to do, like taking care of ailing parents. The pain interferes, to put it mildly:

"I am so overwhelmed with caring for my mom now that she is home. she shouldn't be home because she is an accident waiting to happen. she is at risk for severe falls and has dementia so doesn't know she's not safe to move unattended. it's exhausting. my father is angry and yells at me constantly because he can't yell at my mother. he is deaf in one ear and partially in the other, has no peripheral vision so he can't drive, and he's just miserable and constantly acts it out with me. I am so stressed out which of course makes the ic flare and it's just a big hot mess!

"help is finally coming tomorrow - my sister, and my husband is coming tuesday night. my father expects me to be with him and my mom 24/7. I will do anything for my mom, but my father makes it so unpleasant."

Anne's daughter's graduation also happens around this time, certainly a joy. Also experienced in pain.

- The urological treatments – surgeries - hadn't worked. At this point, many patients turn to other specialists, other health care providers, for help with unrelenting, horrendous symptoms. So did Anne. When we next e-mailed, Anne told me, "I saw a very interesting rheumatologist last week who spent over an hour with me and asked me so many questions. I thought these questions had nothing to do with the pain in my hands that I think are arthritis. His initial thought is I have Sjogren's syndrome, which is an auto-immune disorder. He ordered 8 different blood tests and x-rays of my hands. I go for a follow up on November 9<sup>th</sup>. He has an acupuncture clinic, yoga and uses lots of supplements. He is the first guy I have been impressed with in a very long time. He seemed to have a good working knowledge of ic but was not jumping to offer me anything until all test results were read. I'll keep you posted. The rheumatologist was one of many blind alleys.

"I tried some other things also. I went to a clinic, a spa, hoping that would help with the pain. I was there for three weeks of detoxification, exercise, education, colon cleansing with wheat grass. Hard to tell – detox is awful, and I didn't go off meds because I would have gone into withdrawal. You barely eat, and I lost 15 pounds, but there was nothing different in the bladder. "I also tried an elimination diet every other year – the version advocated at the time. I was going to homeopaths, naturopaths, Chinese herbalists, acupuncture, acupressure, trigger point injections, and elimination diets.

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“I’ve tried everything, and almost ended up in the hospital twice because of over the counter (OTC) supplements that weren’t good for me. I think you have to be as careful with OTC as with allopathic prescriptions. I have been on 45 different medications, both over the counter and prescription. My husband always has a list of what I’m on in case there’s an emergency.

“The only thing I haven’t done is have my bladder out. I won’t do that. Urologists told me it was the only thing left that they could offer.

- Anne finally did have the second neurostimulator removed, in 2011, 2 years after it was implanted.
- In March of 2011 Anne e-mailed me hopefully about her plans to have Botox injections: “Having Botox injections for pelvic floor issues tomorrow. I saw a new doctor in Phoenix who seems to be the go to guy for chronic pain. I have known about him for about 6 months, and it took 4 months to get an appointment. Several reliable sources had treatment from him. Some say they have had miraculous results and some go every 3-6 months for maintenance injections. I am so desperate and my pain is so bad I’ve resorted to crawling around the floor in agony. This is no way to live. Will keep you posted, Anne

In late summer of 2012 I called Anne again – I had not spoken with her since 2011. Anne had been through the Botox treatment, at this point, and it had turned out to be not only ineffective but a miserable ordeal. Anne told me, “The result was that I lost my hair. There was no improvement of symptoms.”

Anne had very good news also, but she wanted to tell me about the Botox and steroid injections first.

“In 2010 I began seeing a gynecologist who specializes in women's pelvic pain. It took months to get an appointment. When I went in for the appointment, I did not see the doctor; his nurse practitioner determines on the first visit if you are ill enough to see the doctor. Lucky for me, I thought, that she decided I was ill enough, and he came in to do a quick internal exam. He told me I had pelvic floor dysfunction(PFD) and possible pudendal nerve entrapment, along with IC. He was sure that the majority of my pain was caused not by the IC, but by the PFD and pudendal nerve entrapment. He recommended 3 series of 20 Botox injections, each series combined with hydrodistentions, and then 3 weeks later 2 series of steroid injections. I agreed to a total of five sessions under general anesthesia. There were Botox injections, 3 separate series of 20 injections each, into the entrapped nerve each time. And two series of steroid injections . with one vial of Kenalog. The result was that I lost my hair. There was no improvement of symptoms.

“Both Botox and steroid injections are done on an outpatient basis. General anesthesia and spinal block is used for the Botox injections, and a spinal block anesthesia for the CT guided steroid injections. I was told I would have minimum pain with both types of treatment. The doctor insisted I have a 30 minute hydrodistention with the first set of 20 injections of Botox, for diagnosis and because he thinks that long hydrodistentions are therapeutically beneficial for

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the treatment of IC symptoms. The next two series of Botox injections would be done with 10 minute hydrodistentions. I was in so much pain and so desperate and he was so sure that it would help me that I agreed. I know I had stated earlier that I would never have another hydrodistention, but after a few years of chronic 8-10 level pain and living my life in bed, I was once again so desperate for pain relief that I gave in. He was so convincing. But this was another big mistake.

“After the first session of 20 Botox injections, accompanied by a 30 minute hydrodistention and 7 hours in recovery, I could not urinate on my own. So they inserted a catheter and said I’d have to have it in for 7 days. No one had mentioned the possibility of this happening. I was devastated, in miserable pain from the injections and the hydrodistention, and was also peeing blood. This continued not for 7 days but for 14 days. They did warn me that I would be peeing some blood for a few days, but not that I would be unable to urinate without a catheter and peeing blood for 14 days. They were very calm and matter of fact about all this, saying it happens all the time, the bladder just goes to sleep with the anesthesia, and it would be fine in another week. I was also so black and blue in my vaginal and rectal areas from the Botox injections, that I was forced to sit on a doughnut with ice packs - another side effect that they failed to mention before the procedures.

“Finally after 14 days I could pee on my own and the urine was a fruit punch color. But there was still no pain relief. They said it would take 3-4 weeks before the Botox kicked in. It finally did kick in and I had *some* pain relief for 6 weeks – but then the pain level went back to 10 again. I did two more rounds of Botox, each with a 10 minute hydrodistention, because they said I needed more.

“Then they did two sessions of CT guided steroid injections. The anesthesia was a saddle block. These were Kenalog steroids. There were 2-3 injections in each session, between vagina and rectum, where the pudendal nerve was supposedly entrapped. These steroid injections didn’t improve my symptoms either!

“Botox and steroid injections did nothing –there was only that short term relief after the first 20 injections of Botox. The people who had recommended the doctor who did the Botox are no longer seeing him either.

“Also, these treatments were not covered under my insurance as they were deemed “experimental.” Each set of Botox injections was about \$5000, which I had to pay up front, a total of \$15,000. Each set of steroid injections was about \$5000 also. The grand total of the 5 sessions was \$25,000., out of pocket. This gives you an idea of how desperate I was.

- Then, by accident, Anne’s daughter’s roommate told her that her own mother had recommended that Anne run, not walk to a physical therapy clinic in Sedona, Arizona, the John F. Barnes “Therapy on the Rocks” clinic, which has been helping people with these problems for 50 years. Anne told me, in 2012, that her first three weeks of myofascial stricture release therapy in September of that year, had cut her pain in half. Anne was and is ecstatic. And I was so



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happy to hear her good news! At this point, the end of March, 2013, Anne says her pain is down 75%.

“The sixteen years of urological treatment I’ve had made my symptoms worse; it was also extremely expensive. My husband and I, and our health insurance company would have saved thousands and thousands of dollars if I’d known, in 1997, when my symptoms began, that what I really needed was myofascial physical therapy. Myofascial therapy is also expensive, but not nearly as costly as all that urological treatment; the first three weeks of intensive myofascial therapy was not reimbursed by my insurance, and I don’t know if the rest of the program will be or not. I hope my story will help change things.”

I asked Anne to describe her experience with this therapy and how it helped her. This is what she wrote:

***Anne’s myofascial release physical therapy (Mfr) experiences***

*I began Myofascial release physical therapy April, 2012, 16 years after the onset of IC, pelvic floor dysfunction and severe chronic pelvic pain. Receiving bi-weekly Myofascial physical therapy treatments, practicing yoga regularly, reducing high oxalate foods from my diet and drinking alkaline balanced spring water has significantly helped to reduce my pain level. I would like to share with you my experiences and insights with Myofascial Release Physical Therapy as it relates to my own journey towards health and healing.*

*My first experience with Myofascial release therapy (Mfr) was with an intensive 3 week program at the John F. Barnes “Therapy on the Rocks” (tor) clinic in Sedona, Az. It was recommended to me by my daughter’s roommate’s mother, who had attended the program years before. As my daughter was describing my health issues and pain level to her, she said, “Tell your mother to run, not walk, to Therapy on the Rocks clinic in Sedona for Myofascial release physical therapy”. So I did just that. I Called Therapy on the Rocks (tor) that day and got the last slot for the intensive program starting the following week. I booked myself for only two weeks initially, but a week and a half into the second week, I had a major breakthrough, so wisely stayed for the third week!*

*Therapy on the Rocks (Tor) is not a fancy spa. It’s a warm and inviting healing center. It’s housed in a creek, old wooden building perched on the side of Oak Creek Canyon in beautiful Sedona, AZ. Upon entering, I felt this place, these therapists and this process was going to change my life if I was willing to surrender and commit myself to the healing process. At 4 thousand dollars a week and my positive attitude, I dove in head first!*

*With each surgery, it creates its own set of adhesions and with each new surgery came more adhesions and restrictions – so instead of making myself well, I was making myself sicker.*

*The John F. Barnes Mfr (myofascial release) intensive program includes 3 hours a day of mfr therapy and several other group classes. The three therapists who worked with me were all incredible people; knowledgeable, caring, supportive, encouraging, skilled professionals who sincerely want to help me heal. Feeling that instant relationship with a therapist for me is very important, as it becomes a very intimate relationship very quickly, especially when you’re having internal work done as I did. For me, Mfr is the therapy I had dreamed about for years. Finally I had found therapists knowledgeable enough to work on the epicenter of my pain, which in my case was internally on my urethra, pelvic floor, bladder and rectum. The work was and still is painful and intense, but getting those restrictions released makes it all worthwhile.*

*The process the body goes through during Mfr therapy when facial restrictions, trapped energy and trauma within the fascia are being released is called “unwinding” in the John F. Barnes Myofascial world. When I finally unwound for the first time, which wasn’t until day nine in the 2<sup>nd</sup> week of my intensive program, it was earth shattering. My entire body shook uncontrollably; my arms and legs were moving in all directions and I was making primal noises that I’d never heard before. That first unwinding*



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session lasted 2 1/2 hours, with 2 separate therapists. It was exhausting. I had never cried that hard or deep in my life. My eyelids were turning inside out with each sob. I was in mourning.

Yes, mourning. Mourning the loss of my former self, before all the labels, all the pain, all the surgeries, procedures and years of disappointments and failures with no sustained improvement. I mourned the wonderful, exciting life I led before illness: long walks with my children, daily work outs, working full time, skiing, horseback riding, Friday night happy hours with my girlfriends and hosting dinner parties for friends and family. I truly mourned the loss of the fabulous sex life my husband and I had shared before I became ill. I mourned it all, and still am.

In almost every Mfr session I have, I unwind. It's like having an out of body experience while being fully conscious. In my most recent therapy session I truly experienced the shedding of a major layer of my pain. If anyone watches the tv series Dexter, he talks about his "dark passenger" his demon that forces him to kill. My dark passenger is pain. It's a heavy, weighty, all encompassing, deep, dark, exhausting, almost go insane, incessant kind of pain, my dark passenger. During these sessions I writhed and cried and moaned and screamed while my therapist encouraged me to go deeper and rid myself of that heavy passenger who is the burning pain. All this is happening while my therapist has two fingers in my vagina, releasing my urethral facial restrictions, and maneuvering a plunger on my back, releasing the restrictions in my lower back from surgery and the scars and adhesions that it left behind. This is what I call exquisite release. During these sessions I feel on the edge of insanity from pain, but then the facial restrictions release and I find sane relief. I am in complete control of the process at all times and can ask my therapist to stop completely or simply ease up. I never choose those options however. I want this over with. I want to go through this pain so I can come out on the other side and I don't want to waste another moment getting there. I have suffered for 16 years and I'm sick of it, so I go full guns. But that's my own personal choice. Each patient is totally in charge of their own healing process.

I feel reborn after the last few sessions. I experienced a healing crisis for a few days after (feel worse before you feel better), but by the third day I realized that my pain had been significantly reduced. Talk about feeling empowered. I was elated!

My pain level has stayed consistently lower and I have significantly reduced my pain meds. Although I still experience pain, it's at a much lower level. I truly believe that with continued MFR treatment I will be completely healed.

I hope by sharing my story and the trials and tribulations of my healing journey that I may be able to save someone the years of suffering that I have endured. If I was diagnosed with IC or any other illness today, my first course of treatment would be the John F. Barnes method of Myofascial Release Physical Therapy. It is the least invasive of all the other treatment options available, and should be the first treatment offered. Unlike the 30 other treatments and surgeries that I put myself through over the years, this one is really helping for me. I pray it will help you too.

Anne continued, "These therapists also taught me about oxalates. Some of the foods I ate the most often were blueberries, pears, and other things on the list of foods "friendly to patients with IC." However, these foods had a high level of oxalates, and oxalates can make IC symptoms much worse.

"Oxalates are acid molecules that are found in many plant foods, which when ingested bind and convert into crystals. These crystals, when passed through the kidneys and bladder, irritate any damaged or inflamed tissue, (as is the case with IC) and exacerbate an already painful organ. Many foods that are high in Oxalates are ironically foods that have been said to be IC friendly foods, like blueberries, pears, green beans and spinach. One site to learn more about Oxalates:

<http://www.ohf.org/docs/Oxalate2008.pdf>

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*Lastly, I need to mention water and alkalinity. Water that is not alkaline is not good for IC symptoms. There has been research that suggests that alkaline neutralized water is better for those of us with IC. I am only using bottled spring water that I have treated with an alkaline neutralizer.*

Conclusion:

From 1997 to 2011 Anne had followed the advice of urologists, the same advice which is given in Statement 10 of the AUA Guidelines: “Patients should be educated about ... the fact that acceptable symptom control may require trials of multiple therapeutic options (including combination therapy) before (acceptable symptom control)... is achieved.”

“What benefit came from this 16 years of misery? Much worse symptoms is what Anne had. The financial cost just to her was probably over \$100,000.. What it cost my insurance company, I don’t know.

“There was 32 years of misery.

“I am very grateful for the myofascial stricture release from physical therapists.

How is it that human beings are allowed to do this to other human beings?

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**3. The Chairs of these three AUA committees responded to our letter by e-mail, on Tue 5/7/2013 4:13 PM, as follows:**

Dear Ms. Zakariassen,

Thank you for your interest in guidelines. We agree that some physicians may not be current in the evaluation and management of chronic pelvic pain including IC/BPS, and we are sympathetic to the plight of the stories that you provide. However, CPP syndromes represent a spectrum of etiologies, and the judicious use of diagnostic and therapeutic procedures remain important in these syndromes.

The AUA guideline creation is a rigorous and thorough evidence-based processing of peer-reviewed articles. This guideline was extensively peer-reviewed and follows the IOM criteria for guideline development. An update literature review is performed biennially, such that future publications could alter the content of the document. We stand by our process of guideline generation. The literature leaves many questions unanswered at this time, and we look forward to a time when the physician has all of the tools and wisdom needed to care for people with this disabling group of symptoms.

Sincerely,

Deborah J Lightner, M.D., Vice Chair of AUA Guidelines

Stuart Wolf, M.D., Chair of AUA Guidelines

Quentin Clemens, M.D., Quality Improvement and Safety Committee, AUA

**What patients tell us actually improved their symptoms of chronic urgency and frequency and pain, a document that will soon be finished:**

**Table of Contents:**

- 1. Wait and See:** As the new urological Guidelines say, and good medical principle dictates, initial treatment should be conservative, i.e. noninvasive, and the body should be given a chance to heal itself.<sup>liv</sup> Patient stories: Ruth and Pam
- 2. Is the routine urinalysis working for all patients? More sensitive urinalyses to detect bladder infections may be necessary.** Urologists may have told you that you don't have an infection – but the standard urinalysis does not pick up all infections, and there are more sensitive urinalyses, specific cultures, (mycoplasma and broth cultures) which have saved these patients from the horrific symptoms of undetected urinary tract infections. You can order the broth culture urinalysis yourself, and ask your urologist to order both the broth culture and the mycoplasma culture. New York Urological

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Associates in New York City already offers the Mycoplasma urinalysis in their office.  
Patient stories: Eleanor and Rebecca

3. **It is becoming more and more clear that many patients diagnosed with IC/PBS have myofascial stricture, and pelvic floor muscle dysfunction (PFMD) caused by surgeries, childbirth, sports injuries and other trauma. These causes of chronic urgency and frequency and pelvic pain can be greatly improved with the appropriate physical therapy by a skilled physical therapist. Because many urologists do not look for these conditions, their patients don't get the appropriate treatment.** One of the urologists who does recognize these conditions says that PFMD “is seen in about 70 percent of IC patients and ....often some of the most pronounced symptoms of IC derive from abnormal muscle activity in this region, rather than from the bladder.” This urologist wrote The Interstitial Cystitis Survival Guide.<sup>liv</sup> Patient and pelvic floor therapist stories: James, David Wise, Isa Herrera, Anne and Hope. Anne's story and James' story, in the letter to the AUA, attached, are very good explanations of how this diagnosis and treatment works.  
<http://www.myofascialrelease.com/resources/articles.aspx>  
<http://www.massagemag.com/News/massage-news.php?id=6745&catid=62&title=t>
4. **Is the heavy use of antibiotics by urologists for treatment of IC/PBS really necessary and beneficial to patients, or do these antibiotics cause damage to our human microbiome and otherwise preventable diseases? In the words of a recent New York Times Sunday Magazine article, “Germs,” “Disorders in our internal ecosystem – a loss of diversity, say, or a proliferation of the ‘wrong’ kinds of microbes – may predispose us to obesity and a whole range of chronic diseases, as well as some infections.”** <http://www.nytimes.com/2013/05/19/magazine/say-hello-to-the-100-trillion-bacteria-that-make-up-your-microbiome.html?pagewanted=all&r=0> The medical specialty of infectious diseases has long recognized that antibiotics cause Candida albicans infection, a fungal disease with many miserable symptoms. The international research project, the Human Microbiome Project, has recently correlated the use of antibiotics since the 1940s and 50s with the explosion of not only obesity, but allergies, asthma, inflammatory bowel disease (IBD), type I diabetes, GERD, heart disease, some cancers, many autoimmune diseases; this may be the tip of the iceberg. Is the overuse of antibiotics in urological treatment for IC/PBS causing preventable diseases and some of the unrelenting, cruel symptoms that patients diagnosed with IC/PBS suffer? And what have patients found to be effective treatment?
5. **How other changes in what we eat have improved patients' symptoms:** a) acid reduction diet, CM's story, b) importance of greens diet, Kathy's story, and c) the IC diet, from the ICA.

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6. **Over the counter supplements and fresh aloe can also reduce symptoms:** Prelief, marshmallow root, quercetin and aloe. Patient stories: Ann, Velma and Inna:
  7. **A list of other causes of the symptoms diagnosed as IC/PBS, and noninvasive treatments** for these causes, as discovered by patients and their health care providers virus, allergies, parasites, celiac disease/gluten intolerance, inadequate nutrition, adrenal fatigue, thyroid dysfunction, Candida infection, Gram negative bacterial infection, Chlamydia Trachomatis (STD), environmental toxins.
  8. **Are the symptoms patients feel actually a diseased bladder, a condition implied by the name – interstitial cystitis/painful bladder – or really many conditions all over the body.** These patients have found effective, noninvasive treatment for these conditions. Patient stories – two pleas that so-called IC/PBS be seen as conditions that involve the whole body: Jennifer and Molly

#### 4. **My/our response to the AUA committees' e-mailed letter/ response, page 61-62**

5/30/13

Dear Drs. Lightner, Wolf and Clemens,

First, we would like to ask, respectfully, whether you have read the letter that Dr. Kavalier and I sent to you.

Our letter did not question the expertise of “some physicians,” but rather the ethics of the 2011 Practice Guidelines, which Guidelines are written by you and other highly placed urologists, and which Guidelines are intended to guide all urologists as to diagnosis and treatment for IC/PBS.

Second, you say that the Guidelines represent “... a rigorous and thorough evidence-based processing of peer-reviewed articles.” Almost every journal article about treatment for IC/PBS admits that treatment is not evidence based. As venerable as “peer review” is for tracking behavior which is not “standard practice,” is “peer review” evidence? One must ask whether peer review that is not based on scientific evidence, is anything but a common opinion among urologists, an opinion which is self-serving and which your latest research has contradicted.

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Patients, who have experienced the treatment for IC/PBS, have told us what doesn't work and what does work. The patients, more than 3 thousand of them, in their responses to our survey and to your trials, have said the treatment is not effective. And we have shown harm. Sadly, you have ignored both the 3000 patients who have responded to our survey, and who were involved in the ICDB, ICCRN and ICCTG trials, and also the researchers themselves.

Third, though you say you are sympathetic to patients, in fact there appears to be a profound disassociation between urologists and patients. Prejudice in favor of the continuation of multiple surgeries is lethal for patients. There are now one hundred million people in the United States with chronic pain, one third of the population;<sup>[1]</sup> it would seem that sympathy for patients would prompt an effort to eliminate unnecessary surgeries.

Prevention of unnecessary surgeries would also help to lower health care costs, which is the scourge of the American economy right now. We know of the variance between counties and countries regarding the numbers of procedures, including surgeries.

[http://www.newyorker.com/reporting/2009/06/01/090601fa\\_fact\\_gawande](http://www.newyorker.com/reporting/2009/06/01/090601fa_fact_gawande) Since chronic pain alone costs more than cancer, heart disease and diabetes combined, more than \$600 billion dollars annually, elimination of unnecessary surgeries would also show concern for the U.S. economy. <http://www.sciencedaily.com/releases/2012/09/120911091100.htm>

Most important is the cost in human pain; there is not only no “adequate symptom control” from the multiple surgeries imposed on patients with a diagnosis of IC/PBS, but more pain.

We will continue to try to inform patients of what is hidden from them about the nature of treatment for IC/PBS, the benefit-to-harm ratio and the alternatives to this treatment. Urologists should be doing this.

Kay Zakariasen