

The IC Optimist

published by the Interstitial Cystitis Network • volume 14, issue 4 • Fall 2017

The Chilling Effect
of the CDC Guidelines
for Chronic Pain

Taking Charge of Pain:
*Tips & Strategies
for Working With
Your Doctor*

Urethral Diverticulum:
*An Unusual Cause
for IC & Pelvic Pain
Symptoms*

How To Stop a
Diet Induced Flare

IC Diet Project:
*Simple & Savory
Holiday Dishes*



Departments

Editorial: ESSIC 2017 - My Daughter's Journey With IC

Latest IC Research • Latest Clinical Trials • Self-Help Tip • Consumer Alerts

Publisher:

Interstitial Cystitis Network
PO Box 2159, Healdsburg, CA 95448
800-928-7496 (Toll-free)
(707) 538-9444 (F)
www.ic-network.com

Subscriptions, Copies & Reprint Requests:

Single issues are available for purchase.
<http://www.icnsales.com>

Featured Writers:

Jennifer Gonzales MSN, APN, ACNS-BC
Samuel Granpsas MD
Jill H. Osborne MA
Stacey Shannon
Bev Laumann
Bryan Mac Murray
Gail Benshabat

Image Credits:

Cover: © feedough
p. 3: © Sevulya
p. 4: © vchal
p. 8: © Popartic
p. 9: © Beaumont Urology
p. 10: © Beaumont Urology
p. 13: © XiXinXing
p. 14: © Stacey Shannon
p. 15: © Jill Osborne
p. 24: © elmosaico
p. 27: © karandaev
p. 28: © Vima
p. 29: © Bella Rosa Coffee Co.

Design & Production:

Tapia Studios (707) 545-7741

Featured Sponsors:

Aquinox Pharmaceuticals
www.aqxpharma.com

Beaumont Urology
www.beaumont.edu/urology

Desert Harvest
<http://www.desertharvest.com>

Prelief/DSE Healthcare LLC
<http://www.prelief.com>

Vista Urology
www.vistaurology.com

CystaQ®
<http://www.cystaq.com>

We welcome freelance query letters and ad submissions for our publications and websites. For additional info: (707) 538-9442 or email jill@ic-network.com

The IC Optimist is distributed electronically or in print format four times a year to subscribers of the Interstitial Cystitis Network, a medical publishing company dedicated to providing information & support for those struggling with interstitial cystitis, overactive bladder, painful bladder syndrome and pelvic pain syndrome. The ICN is a division of J.H. Osborne, Inc.



If you hadn't already heard, the IC Network offices were in the center of the devastating fires that occurred in Santa Rosa, California in October 2017. Without power, internet, phones and even cell phones, we had no choice but to close our main office for almost a month, hence the delay in the production of this magazine. With thousands of homes and businesses burned, we're only just now getting back up to speed. Thank you to everyone who sent prayers and offers of a safe place to stay. You helped keep our spirits up while we were incredibly stressed and, at one point, running for our lives. What a year this has been! ::sigh::

This issue of the IC Optimist covers a very delicate topic - how the lives of IC patients have been disrupted with the implementation of the CDC Guidelines for opioid use in chronic pain. My editorial "Corruption Undenied" shares the story of a DEA whistleblower who cooperated with Sixty Minutes and the Washington Post in a shocking expose about the opioid crisis. Our own Congress & Senate have made the problem substantial worse by crippling DEA investigations.

The harsh reality is that opioid crisis is being driven by diverted pharmaceuticals, the international black market (China) and the illegal drug trade. But, you'd never know that by reading the CDC Guidelines which place the blame squarely on the shoulders of the legitimate pain patient despite research studies showing that chronic pain patients rarely become addicts. Chronic pain providers and patient groups are outraged, pointing to remarkably biased and "bad science" incorporated into the guideline process. In our feature story, we give the history, talking points and the results of our own ICN survey. The patient stories are shocking. We MUST fight back! In the follow up article, "Taking Charge Of Pain," we include dozens of tips to help if you are struggling with pain and working with your physicians.

IC patients are a mystery to be solved. Where is the pain and/or discomfort coming from? Is it the bladder, the muscles, the nerves or perhaps something else? In "When Bladder Treatments Stop Working", we review how the different IC/BPS subtypes can generate slightly different symptoms and require different treatment approaches. There are cases where patients have been misdiagnosed. We share a case study of a patient diagnosed with IC for over ten years who actually had a urethral diverticulum instead. She is now pain and symptom free.

In the latest IC research, we review some of the more exciting new studies released in the past few months, including a possible new urine test which could diagnose a Hunner's lesion thus saving patients from having to undergo (and pay for) a hydrodistention with cystoscopy.

We sponsored Gail Benshabat's trip to the ESSIC meeting last September. In this issue she shares her daughter's story and is dedicated to improving IC care in Canada.

If you are pondering applying for disability insurance, we have an article written by a disability expert that can help you understand the steps necessary for a successful application.

In celebration of the holidays, IC cookbook author Bev Laumann shares some fabulous yet simple recipes for some holiday meals.

From our homes to yours, we wish you a peaceful, joyful holiday season. May 2018 bring you and our country healing, hope, love and laughter.

—Jill, Janice, Donna, Heather & Jenna (the ICN Family)

contents

- 4** ICN Editorial
Corruption Undenied
by Jill Heidi Osborne MA
- 5** The Chilling Effect of the CDC
Guidelines for Chronic Pain
*Some IC Patients Being Forced Off
Pain Medication Without Warning*
by Jill Heidi Osborne MA
- 12** Taking Charge of Pain
*Tips and Strategies for Working
With Your Doctor*
by Jill Heidi Osborne MA
- 16** What Patients Are Saying
About CDC Guidelines
- 18** When Bladder Treatments Don't Work
by Jill Heidi Osborne MA
- 19** Consumer Alert
- 20** The Latest IC Research
- 22** An Unusual Cause of IC & Pelvic Pain Symptoms
by Jennifer Gonzalez MSN, APN, ACNS-BC
& Samuel Granpsas MD
- 24** Self-Help Tip
How To Stop a Diet Induced Flare
by Jill Heidi Osborne MA
- 25** ESSIC Meeting
My Daughter's Journey With IC
by Gail Benshabat
- 28** How to Qualify for Disability Benefits
with Interstitial Cystitis
by Bryan Mac Murray
- 30** Santa Rosa Fire Update
by Jill Heidi Osborne MA
- 31** Clinical Trial Announcements
- 32** The IC Diet Project
Simple & Savory Holiday Dishes
by Bev Laumann



Copyright © 2017. Any reproduction is prohibited without prior written permission from the ICN.

Disclaimer: The Interstitial Cystitis Network website and publications are for informational purposes only. The IC Network is not a medical authority nor do we provide any medical advice. Nothing contained in this publication should be considered medical advice and should not be relied upon as a substitute for consultation with a qualified medical professional. We strongly recommend that you discuss your medical care and treatments with your personal medical care provider. Only that medical professional can, and should, give you medical advice.

Opinions expressed in articles are those of the authors and do not necessarily reflect those of the ICN or its editorial board. The ICN assumes no liability for any material published herein.

Corruption Undenied

by Jill Heidi Osborne MA

This Fall, Sixty Minutes and the Washington Post released a stunning documentary that laid the blame of the opiate crisis on a surprising new source: the US Congress & Senate who passed a bill which virtually crippled the ability of the Drug Enforcement Agency to investigate drug traffickers. It's a classic case of corporate interests manipulating, through lobbying and cash donations, our laws to benefit their ability to make a buck. It's also a disgusting abuse of power that has directly caused the deaths of thousands of citizens. Remember when the Tobacco companies admitted that they increased nicotine levels to increase addiction? This is far, far worse.

Sixty Minutes interviewed Joe Rannazzisi, one of the most important whistleblowers in US History. He ran the DEA's office of Diversion Control, a division that regulates and investigates the pharmaceutical industry. Rannazzisi shared how the opioid crisis was allowed to spread when the US Congress actually limited his ability to investigate companies that were shipping hundreds of millions of pills to suspicious destinations where they were ending up on the streets. Why? Because the pharmaceutical industry is a powerful lobbying force with plenty of money to spend.

"This is an industry out of control" he said, saving most of his anger towards the drug distribution companies (Cardinal Health, McKesson & Amerisource Bergenn) who were ignoring their responsibility under the controlled substances act to report and stop suspicious orders. *"Their goal was to sell a lot of pills and make a lot of money... Greed trumps compliance every time,"* said Jim Geldof, a Pharmaceutical Investigator for the DEA who reported to Joe.

Case in point was a pharmacy in Kermit WV, with a town of 392 people, that ordered 9 million hydrocodone pills over two years.



One distributor alone shipped 28 million pain pills to pharmacies in West Virginia over a five year period, 11 million of which were sent to Mingo County with a population of just 25,000 residents.

Mr. Rannazzisi shared that when the bigger distribution companies started being targeted by the DEA, they mobilized cash and lobbying power to fight back. They went over Joe's head to the Department of Justice and complained. Investigations were then slowed if not stopped by higher level staff in the DEA. Worse, former DEA litigators and investigators changed sides, accepting jobs with high salaries with the drug companies they had originally investigated.

The drug distribution industry wasn't done. They then proposed a new law which eliminated the ability of the DEA to freeze suspicious shipments. They claimed that the DEA was preventing legitimate pain patients from getting their essential pain medication. The bill received little in the way of public and DEA scrutiny, without a single committee hearing held. Rather, it was passed by unanimous consent by both the Senate & Congress, and was eventually signed by President Obama with no registered objection.

Today, we now know that the opiate crisis has irrefutably damaged two generations. Millions of pills were diverted from legitimate use to recreational use resulting in tens of thousands of addicts. More than 100 people die each day by overdosing on opioids with an estimated half million to die across America over the next decade.

The secondary victims of the opioid epidemic are the legitimate pain patients who are no longer being given the medication that they have used responsibly with no signs of addiction. They are being driven to the streets to buy heroin as a replacement and many have pondered suicide. Chronic pain groups around the country continue to demand that the CDC rewrite their guidelines to support those patients who use opiate medication appropriately. I couldn't agree more.

My second college degree was in Pharmacology, the science of drug development. I couldn't be more ashamed of that industry today. We must speak out. We must fight back. We must wrest control of congress away from "big pharma" who care more about their profits than the health and safety of the people of our country. Will you stand with me?

The Chilling Effect of the CDC Guidelines for Chronic Pain

Some IC Patients Being Forced Off Pain Medication Without Warning

by Jill Heidi Osborne MA

When the Centers For Disease Control (CDC) issued their Guidelines for the Treatment of Chronic Pain, they had a noble intent – to reduce deaths relating to opiate overdose.¹ *“With approximately 142 Americans dying every day, America is enduring a death toll equal to September 11th, every three weeks,”* according to the Commission on Combating Drug Addiction and the Opioid Crisis.² Drug overdoses are killing people at a faster rate than the HIV epidemic at its peak.³

Who is to blame? The pharmaceutical industry for distributing millions of pills, often to shady pharmacies? The black marketeers in China who are illegally exporting tons of fentanyl, an opiate 100x stronger than morphine, into the USA?⁴ The drug cartels and illegal drug pushers for cultivating addiction in their users? Or pain patients who take medication and become addicted? Despite research showing that less than 1% of chronic pain patients without any history of opiate addiction become addicts⁵, the CDC Guidelines place the blame almost entirely on their shoulders and has issued guidelines that dramatically reduce and restrict opiate prescriptions even for those patients who have used the medication safely, effectively, in low doses with no signs of addiction.



Essential History

In the mid 1990's, the American Pain Society proposed the concept of pain as the “fifth vital sign.”⁶ They believed that pain patients were being under treated because physicians weren't actively asking about pain during office visits and even hospital stays. The concept was quickly endorsed by various medical organizations who implemented new pain screening tools and methods. Pain patients were thrilled that they were being treated more compassionately.

The pharmaceutical companies saw the potential for profit. They began developing more pain medications and funding publications to encourage their use that minimized their risk. In 1996, Purdue Pharma

embarked on an aggressive campaign to market a new and highly addictive opiate medication, oxycontin, stating that *“They don't wear out; they go on working; they do not have serious medical side effects... these drugs are our best, strongest pain medications, should be used much more that then are for patients in pain.”*⁷ And, much to their delight, pain medication prescriptions increased, dramatically through the 1990's and 2000's. By 2011, doctors had written 219 million prescriptions. In 2012, 259 million prescriptions were written. In fact, the USA consumes 85% of opiates produced in the world.⁸

The illegal drug trade also took notice, setting up marginal “pain clinics” around the country that operated on a cash and carry basis,

prescribing tens of thousands of pain medications indiscriminately. Similarly, some pharmacies were corrupt. One pharmacy in Kermit, West Virginia (population 400) received 9 million opioid pills.⁹ Chinese black marketeers began sending tons of synthetic opioids into the USA for the illegal drug market. Even the Mexican drug cartels started pushing opiates, lacing heroin and others with a splash of fentanyl for the high that it produces.

Today, nearly 2.6 million Americans struggle with opioid addiction, their brain function dramatically changed. “Neurologically speaking, opioids are crafty. They turn the brain’s own electricity against it, rewiring connections in an endless feedback loop for more drugs,” offered Dr. Sandra Block, a neurologist in Buffalo New York. Drug addicts need medication to feel good. They usually have intense urges for the drug that block out other thoughts. They may spend money on the drug even though they can’t afford it. They cannot meet obligations or work responsibilities. Addicts often cut back on social activities and/or may commit risky activities when they are under the influence of the drug, such as committing a robbery for money to pay for drugs.¹⁰

In contrast, chronic pain patients take opioid medication, often at the same low dose for years, so that they can function and be active in their families and their communities. Their motivation isn’t to feel the high but to suppress often agonizing pain. And many patients report that they have never felt a high from their pain medication.

One IC patient shared “I have been on pain medication for the past 2 years. I honestly don’t know how I would’ve gotten through daily life without it. People don’t understand that your body is used to taking it, and you don’t get ‘high’ from it. It simply lessens the pain. I have suffered with IC my entire life...I didn’t know I was able to have a decent quality of life. I work full time and just graduated college. I wouldn’t have been able to make it through my classes without pain medicine. I think that pain



medication should be monitored for addiction and misuse, but I think it’s time to stop looking at all IC patients like they are drug addicts... I would much rather have a pain free life without medication... I was honorably discharged from the military because of IC. As someone who has done all the diets, tried all the medicines, participated in therapies, etc., sometimes pain medicine is necessary no matter what.”

In contrast, chronic pain patients take opioid medication, often at the same low dose for years, so that they can function and be active in their families and their communities.

Medical Community at War

As many IC patients can attest, clinicians are divided about the use

of opioid medication. Many now simply refuse to provide pain care while others are more compassionate and suggest opioids and/or other strategies to reduce suffering and restore quality of life with a special focus on improving a patient’s ability to function in their daily lives. Dr. Daniel Carr, President of the American Academy of Pain Medicine, describes it as “a civil war in the pain community.” He said “One group believes the primary goal of pain treatment is curtailing opioid prescribing. The other group looks at the disability, the human suffering, the expense of chronic pain.”¹¹

In 2015, Dr. Jane Ballantyne, president of Physicians for Responsible Opioid Prescribing (PROP - remember this name), and Dr. Mark Sullivan ignited a flame war online when they published a commentary in the New England Journal of Medicine arguing that chronic pain patients should first focus on their emotional reaction to pain before using medication to reduce the intensity of their pain. “The comments... laid bare a fundamental problem in the debate over opioid treatments: Neither side has much evidence about the benefits or consequence of

long-term use because no such studies exist,” wrote Bob Tedeschi in the medical blog STAT. Some studies have found that opioid users might struggle with an increased risk of depression, anxiety, cognitive impairment. Yet, Dr. Sean Mackey, a past president of the American Academy of Pain medicine and director of Stanford University’s pain management program said that people aren’t talking about the nearly 15,000 people who die per year from using anti-inflammatory medications. He said “Opioids are a tool - they’re more of a fourth or fifth line option for me” as he explores pain treatments with his patients.

Chronic pain experts have urged the CDC to withdraw the guidelines until they are rewritten in an “effort led by pain management specialists, not addiction psychiatrists.”

The CDC Guidelines Under Scrutiny

Our government turned to the **Center for Disease Control and Prevention (CDC)** to develop and issue opioid prescription guidelines. This was unusual because government agencies rarely issue clinical care guidelines. Normally, professional medical associations convene panels of experts to neutrally review research studies and create guidelines without bias, such as the American Urology Association’s Guidelines for the Diagnosis and Treatment of IC/BPS.¹²

The end result was the **CDC Guidelines for Prescribing Opioids for Chronic Pain**. Released in 2016, the document stunned chronic pain clinicians, patient groups and pain experts by recommending dramatic reductions in opioid prescriptions

even for patients who have used them successfully, in low doses and with no signs of addiction. Originally suggested as voluntary guidelines for primary care physicians, they were quickly adapted as mandatory guidelines for Medicare, Medicaid, the VA and assorted insurance companies.

Richard Lawhern predicted dire ramifications in an article for the American Council on Science and Health. “*Even more physicians will leave pain management practice, throwing thousands of patients into the street without medical referral or support when they go into opioid withdrawal. . . . potentially millions more patients will be forcibly tapered down or cut off cold-turkey, plunging them into agony and disability when they can no longer work or maintain family relationships due to the under-treatment of their pain.*”¹³

He and other chronic pain experts have urged the CDC to withdraw the guidelines until they are rewritten in an “effort led by pain management specialists, not addiction psychiatrists. Pain patients or their advocates should be voting members of the writers group.”

Dr. Myron Shank and others have criticized the CDC process for poor science, conflicts of interest and the potential influence of politics. He wrote “*the CDC’s description of the review process. . . fails to document compliance with, or actually documents violation of, most of the IOM’s standards for systematic reviews.*”¹⁴ They excluded all studies conducted outside of the USA. They focused on studies about the dangers of opiate use while minimizing studies which showed benefits. They failed to include any opioid study that lasted less than a year. Yet, they did not reject studies of non-opioid medications that lasted less than a year.

He argued that the CDC guideline process was also politically tainted. Out of 25 contributors and reviewers of the the CDC Guideline committee, “*Seven have highly questionable credentials. Another ten are overtly hostile towards opioid analgesic while there is indirect evidence for such hostility in three more. Only five have credentials and points of view that are distinct from the public positions of the CDC’s director, Tom Frieden*” argued Dr. Shank.

Dr. Frieden is on the record for reducing opioid prescriptions. Dr. Shank continued “*the activities of at least 15 (and arguably 18) of the 25 represent “intellectual conflicts of interests. . . .”*”

Of particular concern was the participation of Dr. Jane Ballantyne, co-author of the 2015 paper mentioned earlier, as well as other members of PROP. She is a paid consultant to attorneys who bring lawsuits against pharmaceutical companies who produce opioids and stands to gain from the new guidelines in the form of more lawsuits. Dr. Shank wrote “*She is one among seven contributors to the CDC guidelines who is also a signatory to a letter, on PROP stationary, demanding that the FDA discriminate against ‘non-cancer pain’ . . . demanding that opioid therapy be limited to low doses for a maximum of ninety days.*”

It appears that the CDC committee was stacked in favor of those who support reducing opioid treatments without allowing for equal participation from chronic pain providers.

It appears that the CDC committee was stacked in favor of those who support reducing opioid treatments without allowing for equal participation from chronic pain providers who would have provided insight into those patients who safely and appropriate use opiate medication.

Chronic pain specialists, advocates and patients have now embarked on a campaign to have the guidelines revised. Surveys have collected tens of thousands of signatures for letters delivered to the current administration. One survey author wrote “*The implementation of the FDA and CDC’s ‘Opioid Prescribing Guidelines’ has*

turned this country's failed 'war on drugs' into a 'war on pain patients.' We have been closely monitored, drug tested and interrogated on the regular for years and even after successful progress, consistent results, and unwavering dedication to follow all the rules, we are being cut back and often times cut off all pain medications that make daily life liveable."¹⁵

Patients are also becoming staunch, informed advocates who are furious that the news media is focusing less on actual research and more on medical media personalities. One patient, Donna J, summarized the issue:

"PROPaganda ... [PROP = "Physicians for Responsible Opioid Prescription", a professional group deeply hated by large numbers of pain patients]... has confused and conflated two different medical issues, chronic pain and drug addiction, as well as padding the numbers by equating prescription medication with illicit heroin and fentanyl... To top it off, they deliberately throw together addiction, dependence, and tolerance as if [they're] all the same. It's bad enough [that] this ignorance is force fed to the average citizen, but the medical community blithely goes along with this charade and abandons and destroys patients who are in desperate need of care... Instead of taking the word of rehab industry stooges, you might want to check with, oh let's see... how about pain management doctors and nurses? Millions of patients have been on stable regimens for years. How did that happen when 'we all know' that's impossible, what with all of us needing increasing doses to oblivion and back due to tolerance?"

I've been on opioids for 12 years, still not an addict, still passing urine analyses, pill counts, compliant and cooperative. But I'm the one who isn't allowed HIPAA privacy and must sign away my rights... [I'm] not allowed to participate in treatment decisions, just do as I'm told; not given any trust or respect, and ... treated like a criminal."¹⁶

In the National Pain Report, Dr. Richard Lawhern called for unity and congressional intervention. He urged legislators and physicians to listen to their patients, not the CDC. "State



and Federal law-makers must introduce legislation and hold public hearings to force recall and rewriting of 2016 CDC Opioid Prescription Guidelines, and repeal State laws that limit treatment of chronic pain patients."¹⁷

Dr. Shank believes that the **National Pain Strategy** document released by the National Institutes of Health in 2010 is far more effective than the CDC Guidelines.¹⁸ It suggests that instead of applying general and broad restrictions on prescriptions of opioid analgesics for chronic pain, they should be prescribed to those patients who clearly demonstrate significant functional improvements because of them. He argues that patients and their physicians deserve guidelines that they can trust.

The Impact on the IC Community

In the Spring of 2017, the ICN surveyed patients to determine if and/or how they have been impacted by the CDC Guidelines. Survey participation is skewed to those patients who struggle with pain and those who have found their medication reduced or discontinued. Clearly, the data cannot be used to make broad conclusions about the IC patient community as a whole.

Most patients participating in this survey have more intense pain that has reduced their ability to function and/or work. Some have struggled to find medical care providers who will treat their pain. Even doctors who believe that their pain is intense have told patients that they must reduce their dosages and/or stop pain medication because of the CDC guide-

lines. Most patients are deeply worried about future pain treatment.

Widespread Effects

Of the 386 patients who completed the survey, 50% experience pain daily and 42% experience pain every hour of the day. 6% reported pain once a week.

The majority of those patients (55%) reported that their pain levels are moderate and stop them from doing their daily tasks and/or work that they need to do. 28% say that their pain is so intense that they rarely leave their homes. 17% said that their pain was mild and that it didn't stop them from doing their daily tasks.

Only 50% used pain medication daily. 11% used them once or twice per month, 8% once or twice per year, 5% one or twice per week and another 5% once or twice a quarter. 12% hadn't needed to use pain medication in the past year.

One IC patient wrote *"I never take anything I don't absolutely need. I don't drink or use pot so I'm not into getting high. Both are legal in my state and I don't use either. My PC said he HAS to take me off of pain medication and that*

no one else will help me. If I walked in today I wouldn't get anything. My pain is very severe and I have no advocate to explain this to the government. I'm not addicted and not abusing. I'm in dire pain."

Only 4% of patients were told that their doctors were concerned that they may have developed an addiction to pain medicine.

Prescription Changes

Clinicians gave little advance warning about changes in pain medication. 22% of survey respondents were told that their current prescription would be their last. 22% were told that they would eventually stop their medication and a whopping 52% were simply refused any additional pain care.

An IC patient shared her outrage at being treated like an addict. "I

have taken the same doses of tramadol and diazepam for the past ~8 years, now. It does a pretty good job of controlling the pain so I can function. I have never taken an increased dosage of either, and always take less than the amount which is prescribed. However, I feel like I am treated like a common criminal – drug tested, given a hard time about refills, people assume I take the Valium for "nerves," etc. It is humiliating to be treated in this manner, and this is at a major university medical center. Unfortunately, the one urologist there who specialized in IC left a couple of years ago, and his NP (who also understood what IC patients go through) has retired."

The decision to cut off medications was explained in several ways. Some clinics told patients (32%) they were following the new CDC guidelines. Some physicians (27%) said that they were personally choosing not to provide pain treatment while others (24%) stated that they were worried about being targeted by the DEA for providing pain care. 9% were told that the doctor was concerned they were using too much pain medication. Only 4% of patients were told that their doctors were concerned that they may have developed an addiction to pain medicine.

Because opiate medications can cause drug tolerance, disabling withdrawal symptoms can occur if the medication is not tapered slowly down. In our survey, 44% of patients were offered no transition plan and were forced into withdrawal with no assistance. Only 11% of patients were given a tapered dosage down to prevent withdrawal.

Worry about withdrawal symptoms was common. One patient shared *"I feel defeated because my doctor says he is referring me to a pain specialist who will work with me to reduce the amount of pain meds I'm currently on. I'm terrified of withdrawal and my quality of life once my pain meds are gone. I will no longer be able to work and support my family. I don't want to live on welfare but I won't have a choice if I don't have the meds that help me to make it through the day as it*

Not All IC Patients Struggle with Pain

It's important that our readers understand that not all IC patients have needed or required pain medicine, nor should they assume that intense pain is in their future. The great challenge of IC/BPS is identifying which, of several, subtypes is causing their pain and urinary symptoms (i.e. Hunner's lesions, bladder wall injury, muscle dysfunction, neuralgia and/or central sensitization). The goal, over the long term, is to reduce the need for pain care by treating the original source of the pain correctly.

Some of the patients who participated in this survey have taken pain medicine for years, long before the subtypes were developed. Because they may not have received the correct treatment for

their unique case of IC, their pain may be more intense or chronic. Their stories and quotes shared in the survey are daunting. Please remember that their stories are uniquely their own. They may have other medical conditions that have contributed to their pain. They may have untreated Hunner's lesions. They may not have been able to afford treatment. They may be in denial and drinking a pot of coffee a day (or other acidic foods) which can cause more pain for patients with a bladder wall subtype. By sharing this data and their stories, we hope to provide ammunition which can be used by patients and pain advocates to demand that the CDC Guidelines be re-written.

is. *I'm terrified.*"

Referrals to pain clinics were made for 27% of our survey participants but they received mixed reviews. 28% of those patients who visited pain clinics received no assistance for their pain and were instructed to stop all medication. 32% reported that the clinics had no experience with IC and didn't believe that IC could cause severe pain. Only 30% reported that they were respectful and provided some pain medication. Only 11% reported that the pain clinic had helped them find new ways to manage their pain. It's not unusual for pain clinics to refer patients back to their primary care providers for pain treatment.

32% reported that the clinics had no experience with IC and didn't believe that IC could cause severe pain.

77% of survey respondents are very worried about their future pain care while 17% are somewhat worried. Only 5% are not worried.

Pain medicine allowed many patients to continue to work. One patient shared *"I am concerned that I may have to stop working in the future when pain is too severe and I don't have adequate medication to treat it."*

OTC Products

Given the more intense pain levels often experienced by IC patients, it comes as no surprise that most (81%) found OTC pain relievers unhelpful. Advil (12%), Tylenol (8%) and Aleve (6%) were modestly helpful for some patients.

Over the counter essential oils have a small following in the IC patient community though 56% of participants reported that they had never tried them. Aspercreme (10%) and Tiger Balm (7%) were the favorites though several smaller

brands were mentioned, such as: Kayala Pain Rub, Young Living Panaway Rub, Australian Dream MSM oil, DoTerra Deep Blue Rub and Walmar's Vagicaine (a lidocaine product).

Medical marijuana and CBD oil are used by some patients. 11% of participants shared that it's legal in their states and they have a prescription for it. 8% say that they've tried it even though it's not legal. 72% have not tried any medical marijuana products. Of those who use MMJ, 6% said that it helped greatly and they no longer need other pain medicine. 23% report that it does help reduce their pain but they still need some pain medication. 12% reported that it did not help their pain at all. Several patients noted that they were unable to try MMJ because their pain clinic requires monthly urine testing and that they would be kicked out of the clinic if they tested positive for it.

One patient uses CBD pills. *"IC has changed my life in EVERY dimension. It is horrific that this level of pain is considered "part of IC" and we are not given real pain relief. After 5 years of IC, the ONLY true pain relief I've had is CBD pills - the non psychoactive part of marijuana that helps with pain. \$1 a pill but it works, but then wears off. Tramadol helps but gives me a little "high" I don't like and makes me too hyper, then sleepy. Please tell people about medical marijuana or CBD!"*

Location of Pain

It's always interesting to ask patients if they know where their pain is coming from. 73% believed that it was coming from their bladder wall (21% from Hunner's lesions). Another 59% believed that their pelvic floor was contributing to their pain or that the pain was coming from their nerves.

26% of the patients participating in the survey had been diagnosed with Hunner's lesions, 60% without. A remarkable 14% did not know if they had Hunner's lesions. This is an important diagnostic question for patients to ask if they are struggling

with long term chronic pain because pain can be reduced often dramatically with Hunner's lesions treatment (cauterization, steroid injection, LiRIS/LINKA currently in clinical trials).

57% of patients had been diagnosed with pelvic floor dysfunction. Of these patients, 3% said that physical therapy dramatically improved their pain. 24% said it helped improve one of their pain and 22% said it didn't help. 28% were unable to try physical therapy because it wasn't covered by their insurance or they couldn't find a physical therapist to help.

Diet

Eighty percent of participants reported that some foods make their symptoms worse and that they avoid those foods. Tragically, 11% reported that they eat acidic, irritating foods or beverage even though they cause pain not understanding that they could be perpetuating bladder wall injury and neuroinflammation. We often see this in patients with Hunner's lesions and/or bladder wall injury who continue to drink coffee, tea or soda on a daily basis. It is difficult if not impossible for the bladder wall to heal when it is being irritated by high amounts of acid each day. Not surprisingly, 9% reported that foods have never bothered their bladders clearly reflecting that their IC/BPS subtype is probably muscular rather than bladder wall driven.

References

1. CDC Guideline for Prescribing Opioids for Chronic Pain. Centers For Disease Control and Prevention. Last updated August 29, 2017 - <https://www.cdc.gov/drugoverdose/prescribing/guideline.html>
2. Goodnaugh A. White House Panel Recommends Declaring National Emergency on Opiates. The New York Times. July 31, 2017
3. Katz J. The first count of fentanyl deaths in 2016: Up 540% in three years. New York Times. September 2, 2017. https://www.nytimes.com/interactive/2017/09/02/upshot/fentanyl-drug-overdose-deaths.html?_r=0
4. Scipioni J. DEA: Made-in-China Lethal

Opioid Fueling U.S. Drug Epidemic. Fox Business. March 31, 2017.

5. Noble M et al. Opioids for long-term treatment for non cancer pain. Cochrane. January 20, 2010

6. Campbell JN. APS 1995 Presidential address. Pain Forum. 1996;5:85–8.

7. Moghe, S. Opioid History: From ‘wonder drug’ to abuse epidemic. October 14, 2016

8. American Society of Addiction Medicine - Opioid Addiction 2016 Facts & Figures - <https://www.asam.org/docs/default-source/advocacy/opioid-addiction-disease-facts-figures.pdf>

9. Eyre E. Flooded with pain pills, a WV town strikes back against drug distributors. Charleston Gazette-Mail. Jan 31, 2017 |

10. Block S. What the opioid epidemic looks like on the screen of a brain scan. The Washington Post. Dec. 1, 2017

11. Tedeschi B. A ‘civil war’ over painkillers rips apart the medical community — and leaves patients in fear. Stat. January 17, 2017

12. Hanno, et al. Guidelines for the Diagnosis and Treatment of Interstitial Cystitis / Bladder Pain Syndrome. AUA 2011

13. Lawhern R., The CDC Opioid Guidelines Violate Standards of Science Research. American Council on Science and Health. March 25, 2017.

14. Shank M. Critique of the CDC’s Draft Guidelines on the Use of Opioid Analgesics for Chronic Pain Part One. 12/31/15 <https://drshank.wordpress.com/2015/12/31/critique-of-the-cdcs-draft-guidelines-on-the-use-of-opioid-analgesics-for-chronic-pain-part-one/>

15. Repeal the FDA CDC Opioid Guidelines Now - Stand United. <https://www.standunited.org/petition/repeal-the-fdacdc-opioid-guidelines-now>

16. Lawhern R. Doctors and Legislators: Listen to Patients, Not The CDC. American Council on Science and Health. January 24 2017 -

<https://www.acsh.org/news/2017/01/24/doctors-and-legislators%C2%A0listen-patients-not-cdc-10758>

17. Lawhern R. Stop The War Against Pain Patients! A Point Paper for Lobbying

Legislators. National Pain Report. August 11, 2017

18. National Pain Strategy: A comprehensive Population Health-Level Strategy for Pain. 2010. National Institutes Of Health - <http://iprcc.nih.gov/docs/DraftHHSNationalPainStrategy.pdf>



Taking Charge of Pain

Tips and Strategies for Working with Your Doctor

by Jill Heidi Osborne MA

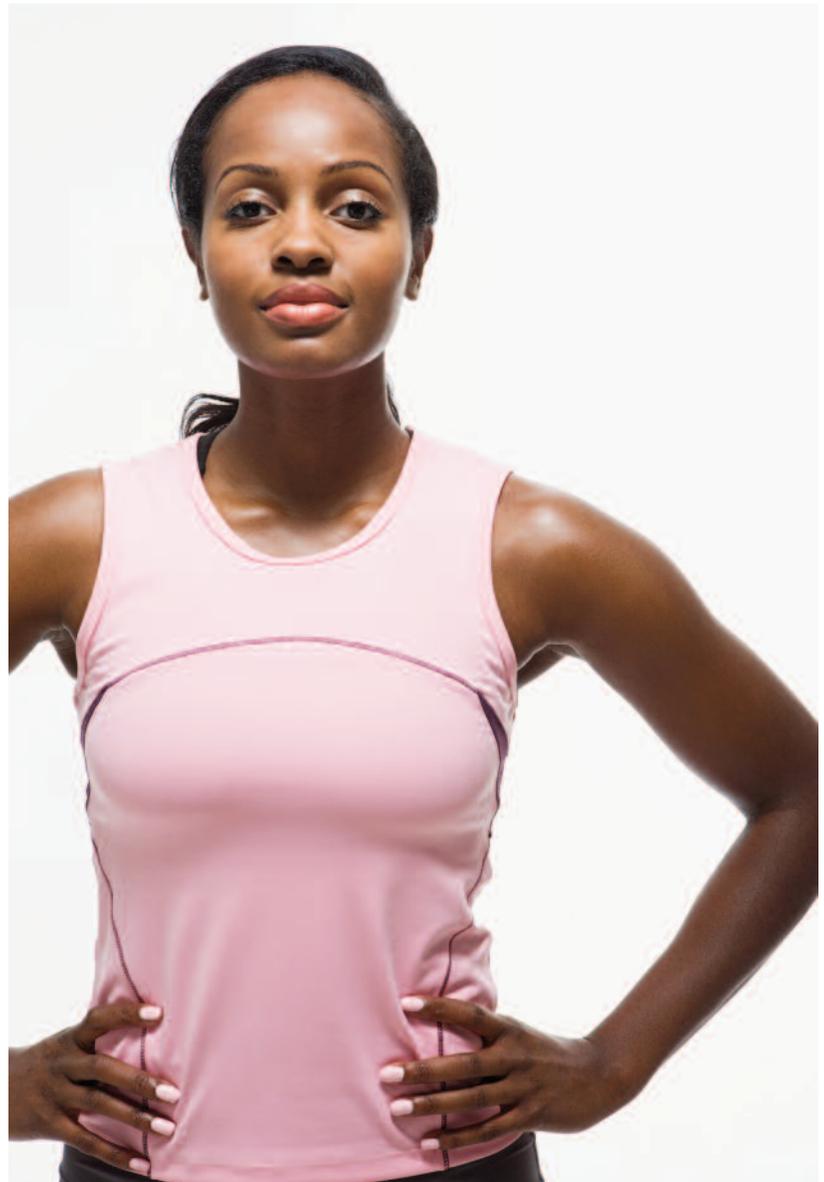
Your goal is not just to treat the pain but to discover the source and cause of the pain. Focus first on your unique anatomy by asking “*What specifically could be causing this type of pain?*” Do you know if it’s your bladder wall or your pelvic floor or perhaps nerves? This vital question provides the foundation for your future treatments.

What do your symptoms tell you?

Your symptoms provide the first clues. Pain as the bladder fills with urine that is relieved by urination points to the bladder wall and/or Hunner’s lesions as the source of pain. Pain after urination, as well as a sensation of heaviness, downward pressure, difficulty starting your urine stream or pain with intimacy usually originates from pelvic floor muscles and dysfunction. Searing, electrical pain that changes with positions (i.e. such as sitting) suggests pudendal neuralgia and/or an entrapped nerve. Patients who struggle with other painful conditions such as IBS & vulvodynia may have central sensitization (aka a more sensitive nervous system) that is often characterized by sensitive skin, food, drug and chemical sensitivity and, notably, a remarkably sensitive sense of smell. For these patients, the goal is to calm the down the nervous system. Sound familiar? These are the subtypes suggested by Dr. Christopher Payne.¹

Are you guessing about what is causing your pain or do you have facts?

Pain that persists longer the three



to six months deserves more than a guess. You should be asking for facts gained through testing. Are urine cultures negative? Has a pelvic floor assessment been completed? Is the bladder tender? Are muscles tight? For obvious bladder wall pain, has the bladder wall been examined through a cystoscopy to rule out other potential problems. Has any medical imaging been done to look at other structures in the pelvis, such as endometriosis and so forth?

In this issue of the IC Optimist, we share the story of an IC patient who had suffered for years with bladder and urethral pain. Using a cross section MRI of her pelvis, they eventually found a urethral diverticulum extending the length of her urethra. When it was surgically

removed, all of her IC symptoms disappeared. Tarlov cysts in the lower back can also cause IC symptoms.

Pain is a powerful justification for additional testing but you also have the right to ask for some short term relief for any pain that might occur because of the testing, such as if you have a hydrodistention with cystoscopy. Most urologists will provide pain medication after the treatment. The AUA now recommends that hydrodistentions be performed with a lower pressure and a shorter duration to reduce trauma and post-operative pain.

Are you justifying your need for pain care by tracking your symptoms?

The American Urology Guidelines

for IC/BPS encourage doctors to assess pain at every single doctors appointments. It is very important that you assist your doctor in understanding your pain by bringing both voiding and pain diaries to each appointment. These should be placed in your medical files so that they can track your symptoms. Remember, pain is subjective, not objective. But when you bring a voiding diary that shows how frequently you urinate, how often you are up at night that also tracks your pain on a scale of 1-10 is powerful ammunition for you to use when asking for pain care. These records are also very helpful for patients who are applying for disability insurance because they track symptoms over time.

Are you just relying on pain medication?

Pain care is not just about using pain medication. It's about using other strategies and self-help tips that can help moderate your pain. If, for example, you struggle with muscle tension, then consider stretching, doing physical therapy, taking hot baths to relax muscles, avoiding things which can worsen muscle tension, using guided relaxation techniques and, if necessary, using muscle relaxants.

If you struggle with bladder wall pain, then following the diet is an absolute must.² If you are continuing to drink coffees and sodas which you know irritate your bladder, then you are also to blame. Your job is to create an environment which will support healing of your bladder and calming of the nerves that are generating that pain.

Patients with central sensitization, myself included, must work hard to avoid overstimulating nerves. We do better in a quieter, less stressful environment. We must avoid foods like caffeine or chocolate which are neurostimulatory. We often have to remove chemicals from our homes that can irritate our more sensitive nerves. We also have to address any anxiety or depression that is happening. Remember that stress can increase the pain response so we want to be very proactive with stress and anxiety.

A quick visit to our website will give you many more tips that you can use at home - <https://www.ic-network.com/interstitial-cystitis-resources/>

Are you fighting flares & pain early?

The secret to fighting pain and IC

The source of your pain is the mystery you and your doctor are trying to solve.

flares is to catch it as early as possible before the pain cycle and nervous system are fully involved. Don't wait until you are crying before you act. The **ICN Flare Management Guide** offers hour by hour rescue plans that can help you nip a flare in the bud before it gets out of control.

Are you struggling to talk with your doctor?

The worst thing that you can do is walk into a doctors office and start crying. You need to be calm, collected, informed and ready to be your own best advocate. Your job is to give your doctors a road map for your body and your pain. The source of your pain is the mystery you and your doctor are trying to solve. Before you visit the doctor, ask yourself the following questions:

- Where is your pain? Be specific. Is it internal (inside of your body) or external (outside of your body your skin)? Is it low by your legs or high by your belly button? Is it on the front of your body (abdomen) or on the back of your body? Tell them exactly where it is. Is it by your rectum? Your urethra? Your vulva? Your testicles? If you don't know where these are, a simple google search will give you plenty of diagrams so that you can learn where these important structures are. You should know where your urethra is before you visit the doctor and if you don't, you'll look foolish. (You'd be amazed by the number of people

who don't.)

- Grab a mirror and LOOK AT YOUR BODY and all the structures in your crotch! For women, it's the vulva, clitoris & clitoral hood, urethra, vagina, bladder and rectum. For men, the penis, scrotum and rectum. If something hurts, look at it first. Does it look different? Is it red? Swollen? Have bumps? Your ability to describe where your pain is could point your doctor in the right way quickly.

- Do you have any unusual symptoms? Pain with sex? Painful arousal? Pain when sitting or driving? Pain when walking? Leakage? Tell them!

- When is your pain the worst? In the morning, after you eat, and/or when you try to sleep?

- What helps your pain? When you drink water? Eat? Move? Use heat? Use cold? Use an OTC pain relief product?

- Does your pain change throughout the day?

- Is your pain worse today than it was a week ago, a month ago or a year ago?

Do you have your medical files?

Bring your medical history with you. Organize it thoroughly by date, preferably in a binder, including the test dates, results, treatments and so forth. Also include your voiding and pain diaries. Show your doctor that you are a responsible participant in your health care. If you don't have one, you can download a medical records kit here: <https://www.ic-network.com/downloads/icnmedical-recordsfile.pdf>

Talk FIRST about your functionality.

An addict uses pain medication to escape life. A pain patient uses pain medication so that they can function, work and be responsible. This is the image you always need to present. Talk first with your doctor about your functionality. Are you unable to work? to drive? to shop? to go church? Tell the doctor that your goal is to be able to function. Ask what suggestions she or he may have to help you restore your ability to function. This allows your doctor to bring up and discuss a variety of treatments, including pain care.

Do you know the different types of pain medication?

There are many different types of pain medication, from OTC products to opioid medications and beyond. But even opioid medications have differences. Some opiates are very short term, lasting up to 4 hours (i.e. Vicodin) while others are time release and are meant to last longer. (i.e. Oxycontin). Some opiates are weak (i.e. Tramadol), while others are very, very strong (i.e. Fentanyl). Take some time to learn about the different types of medications that are available. If your doctor is unwilling to provide one type, perhaps you can suggest another. Learn more here - <https://www.ic-network.com/interstitial-cystitis-resources/pain-resource-center/#principles>

Are you afraid of being examined?

You might be surprised at how often patients say they are afraid of the examination. Some patients are very uncomfortable with intimate examinations that involve looking at your private parts and/or touching the vagina or rectum. Don't be afraid of this exam. It is very, VERY important because this is how your doctor can determine where your pain could be coming from. It is essential that they perform a quick vaginal and/or rectal exam. For women, the doctor should also look more closely at the quality and health of your skin and

potentially show estrogen atrophy. If your vulva or vagina is dry, then so is your urethra and bladder. Estrogen atrophy is a normal part of aging that can be treated.

Does your doctor and/or pain clinic not know about IC?

If you're encountering doctors who don't know or understand what IC is, bring a copy of the AUA Guidelines for IC/BPS. It's about 50 pages long but includes several detailed discussions about pain treatment and supports the use of opioid (and other) pain medication if necessary. It's better for them to have an official document from the medical association rather than a website print out. You can download it here: [http://www.auanet.org/guidelines/interstitial-cystitis/bladder-pain-syndrome-\(2011-amended-2014\)](http://www.auanet.org/guidelines/interstitial-cystitis/bladder-pain-syndrome-(2011-amended-2014))

Are you struggling to find a doctor or physical therapist?

The following websites have searchable databases:

Interstitial Cystitis Network - www.ic-network.com

International Pelvic Pain Society - www.pelvicpain.org

American Urology Association - www.urologyhealth.org

American Urogynecology Association - www.voicesforpdf.org

Herman Wallace Institute - www.hermanwallcecom

Struggling to pay for treatments?

If you aren't covered by insurance or can't afford treatment, you are certainly not alone. Participating in a clinical trial is one way that you can meet with world class physicians. Diagnostic procedures and treatments are usually free and some trials may pay you for participation. Look for trials at: <http://www.clinicaltrials.gov>

If medications have become too costly you have two options. Look first for a compassionate use or drug assistance program offered by the pharmaceutical company that makes your medication. If you meet their income requirements, you could get your medication for free or at a reduced dose. Our website has a drug assistance resource center where you can learn more about this. <https://www.ic-network.com/drug-assistance/>

If you do not meet their income requirements and/or simply can't afford the medication, there are a variety of OTC supplements that might be helpful: CystoProtek, Cysto Renew, Desert Harvest Aloe, Cysta Q and Preief. Each cost under \$50 a month and some have clinical trials showing success at reducing the symptoms of IC. You can easily stretch these out by reducing dosages to make one bottle last up to three or four months.

Are you afraid to try physical therapy because it hurts?

We often encounter patients who go to the physical therapist once and then give up because that visit was painful. Muscle tension requires muscle work. And, of course, when they are trying to find the dysfunctional muscles, they have to gently touch and push on muscles to see what hurts. In that first visit, pain is actually success because it means that they've identified the source of the pain. This is great news! Followup visits are generally much less painful because the physical therapist now knows where your pain is. During PT, their goal is to gently stretch and work muscles to restore their function. If it hurts, speak out! Tell them to back off a little bit. Be vocal. Rest assured that



the vast majority of patients who try PT respond well to it, myself included.

Are you afraid to be catheterized?

Some patients fear catheters and/or other instruments that are inserted through the urethra and into the bladder because they cause pain. Generally this can be caused by very tight muscles around the urethra, a narrow urethra (aka urethral stricture) or a very dry urethra. Some patients may need to work first on their muscles with some physical therapy and/or using muscle relaxants. Patients with a dry urethra due to estrogen atrophy may need to use some estrogen cream over time to help produce some protective mucous. In both cases, plenty of lubrication can help a catheter slide easily in and out. You can also request smaller catheters (i.e. pediatric French size 8 or 10) and/or low friction catheters.

Have treatments hurt you in the past?

Are you afraid to try bladder treatments (for IC Subtype 2) because they have hurt in the past? Well, again, you are certainly not alone. Older patients who were diagnosed with IC a decade or longer were often exposed to old, outdated treatments that WERE quite painful. Silver nitrate and chlorpactin are notorious for causing severe pain and are no longer used for the treatment for IC. They are not even mentioned in the AUA IC Treatment Guidelines. Even DMSO, the only FDA approved bladder instillation for IC, can be painful when used at the full dosage. Rather, DMSO is usually used in a cocktail form with other medications to help reduce any irritation and trauma.

The most popular bladder instillation today is a rescue instillation made of heparin (or Elmiron) and lidocaine. It's called a rescue treatment because the lidocaine (or marcaine) usually numbs the bladder wall, stopping the pain almost instantly. The heparin or Elmiron acts as a bladder coating. Some physicians add a steroid or an antibiotic to the mix. Some patients can do these instillations at home. (Some

patients may be intolerant to lidocaine but may tolerate marcaine.)

If a treatment hurt you in the past, tell your doctor about your experience. Ask if they can do anything that will make it less painful or stressful. Ask if there is another treatment you can do instead?

Are you managing your stress and anxiety?

Whether you want to admit it or not, stress is a well known trigger for IC flares and can exacerbate and intensify our pain experience. It's very important that we keep stress levels as low as possible. If you struggle with high stress, you must learn some new and better skills to keep that stress from worsening your IC. You may find taking a class in stress or cognitive behavioral therapy may be helpful. Talking with a therapist, counselor or religious advisor may be helpful. Creating a peaceful space in your home and simplifying expectations for yourself are very important to those recovering from chronic illness and managing pain.

Are you practicing deep breathing yet?

One of the easiest ways to reduce stress and improve your overall health is to practice deep breathing, especially when struggling with pain and/or stress. Deep breathing helps your muscles and pelvic floor to relax. It delivers oxygen deeply into your body, improving muscle health, function and physical stamina. It helps the release of toxins and emotional distress. Deep breathing can reduce your blood pressure and make your heart stronger. It can boost your energy levels and mood. Most importantly, deep breathing triggers the release of endorphins which are your bodies natural pain killers.³

References

1. Payne C. A New Approach To Urologic Chronic Pelvic Pain Syndromes: Applying Oncologic Principles To 'Benign' Conditions. Current Bladder Dysfunct Rep. Topical Collection on Pelvic Pain. March 2015
2. Osborne J. Diet Modification Can Reduce Bladder Symptoms and Pain. Interstitial Cystitis Network. January 22, 2016 - <https://www.ic-network.com/intersti->

<http://www.onepowerfulword.com/2010/10/tial-cystitis-diet/why-some-foods-hurt-the-bladder/>

3. Srivastava A. 18 Benefits of Deep Breathing and How To Breathe Deeply. One Powerful Word. 10/18/2010 - <http://www.onepowerfulword.com/2010/10/>

What Patients Are Saying About CDC Guidelines

As a man I am less able to get compassionate care for my IC due to outdated notions IC is a woman" disease.

•••

I am no longer willing to be a participant in the medical system as it has failed me.

•••

I have been on pain medication for the past 2 years. I honestly don't know how I would've gotten through daily life without it. People don't understand that your body is used to taking it, and you don't get "high" from it. It simply lessens the pain. I have suffered with IC my entire life, but it has gotten worse since I have gotten older. I didn't know I was able to have a decent quality of life. I work fulltime and just graduated college. I wouldn't have been able to make it through my classes without pain medicine. I think that pain medication should be monitored for addiction and misuse, but I think it's time to stop looking at all IC patients like they are drug addicts. I didn't ask for this illness. I couldn't prevent. It can't be cured. I would much rather have a pain free life without medication. Why would anyone want to be limited in everything that they can do. Every single thing I do in life is planned around having a nearby bathroom, only being able to work certain jobs, and doing everything to prevent a flare. I was honorably discharged from the military because of IC. As someone who has done all the diets, tried all the medicines, participated in therapies, etc., sometimes pain medicine is necessary no matter what.

Cut off with no notice or explanation

Walking. Sleeping. Sex. IC affects these areas of my life and more. The pain clinic cut me off from the pain med I was on for a couple years, with zero warning or explanation. My gp and urologist are bound by company policies that prevent them

from writing scripts for opioid/narcotic pain meds. The pain clinic that dumped me is the only one in my county that accepts my insurance type AND writes for pain meds. I was never late, never cancelled an appointment, and followed all of their rules to the letter!

Functionality

While on the correct dosage of pain medication, I could lead a productive, somewhat normal life. People couldn't even tell I had a chronic pain illness bc of my high functionality. Without it, there is no hope of leading a normal life, as daily activities and work hours are near impossible to withstand.

•••

Narcotics are so tricky. I had this condition for years and tried everything under the sun. Every western medicine and eastern medicine option. Yoga, acupuncture, PT. Every medication. I have a full box of medications in my closet (meds that I tried, didn't work). I went through invasive procedures to try to get a diagnosis. I spent my life savings (about 5k) on PT that I couldn't afford- insurance doesn't cover it. Not one single thing brought an ounce of relief. After years of suffering, not sleeping for more than 2 hours at night, quitting my job due to the pain, my PCP suggested trying oxycodone. To say that it was life changing is an understatement. It brought pain relief without ANY side effects. Not one. When I hear about a pharmacy narcotics robbery so that people can get "high," I honestly wonder what that feels like. I've never felt any euphoria. The way I describe it to people, is that after 30 minutes, the pain in my pelvis dissolves away, kind of like a cloud breaking up in the morning sun. I got my life back. I could get out of my apartment. Go on walks. Actually sit in a cafe and have a drink with friends (before, I would be in so

much pain that I would be biting the inside of my lips that I wouldn't scream). I can actually enjoy events. I can go to concerts. I can travel. I went back to full-time work. I finished graduate school. I'm doing more graduate school now. I sleep 8 hours at night. My relationships have improved. Oxycodone has given me my life back. However, there's this dark cloud looming over my head. I know that at any time, my PCP can decide to stop prescribing on a whim. They are constantly new surveillance of prescribers and my doctor is scared. Most of the doctors in the practice "won't touch the stuff." Even if my doctor decides to move or change practices, I don't know what I will do. I am scared of losing my actual medication, whether it be losing my purse, misplacing it, having someone steal it, etc. There is such a public war going on with narcotics. At family gatherings my family members talk about how terrible narcotics are, and how awful addicts are. They talk about how chronic pain patients are no different than addicts. Little do they know, that I am in this group they are talking about. At school they teach us that you can tell who is on narcotics by their pupils, this makes me scared to look anyone who is medical savvy in the eyes. At doctors appts (outside of my PCP), I never say that I'm on narcotics. Once I do, the environment of the appointment completely changes. The docs stop making eye contact with me and dismiss me. When I don't bring up the fact that I'm on narcotics, I am treated much different. Due to all of this and more, I'm exhausted. We need a change in mentality about narcotics, and also IC patients and narcotics. There has been a shift in mental health perception-- medical professionals are pushing for this to be recognized as a DISEASE that needs TREATMENT, rather than a downfall of someones individual self.

So why can't we, as IC patients, be perceived as patients who need TREATMENT. There needs to be a shift in perception for pain management of this condition.

...

Having the use of opiate medication to control my severe IC and pelvic floor dysfunction has changed my life in an extreme positive manner. I initially never ever left the house and was in the bed with heating pads ice packs all day, all the time. The sedentary lifestyle through my triglycerides to 230, the weight gain with severe the muscle mass loss was severe I was within heart attack range from the sedentary lifestyle. I now can function and attend my childrens softball, cheerleading, baseball. For years I could not attend at all. I can now manage my home in doing laundry and small tasks around the house. The quality of life, receiving opiate medication, has increased 90 to 100%.

...

I do not feel like people who take opiate pain medication should be punished for what other people do. We are grown adults not children on a playground. I also feel like drug addicts often use that they were once on pain medication or got hurt as an excuse and that's written down and noted as the truth. I've asked a lot of people... trying to gain my own perspective because I just could not imagine that anyone would take this medication willingly or would want to for recreation. It confused me and I could not understand that. And whenever I would just ask people and have them ask their friends ...and so on... and pull in simple surveys for myself ..they all said that they lied to doctors that they started with a prescription. I asked him were they able or did the doctor trace the prescription back to see what dates they took a prescription opiate and how much initially and they all said no. I think all of this has been a lie and a manipulation. The addicts said

that they particularly don't care for the medicines that IC patients mostly take. They're nowhere near strong enough and not the type of opiates they like. So that's my two cents and I'm willing to do whatever is needed to do to make sure that grown adults ...who can manage their own life and their own medications... are allowed to do so.

...

The street fentanyl problem has increased awareness of the drug and I feel I am being judged negatively for needing it. It makes me anxious and embarrassed on top of having to deal with IC -it gets to be too much, wish people would be more understanding about how I would not function without pain treatment. I am a highly active and successful person that would be disabled without pain management. I felt like we were making progress but this latest policy activity I feel has pushed us backwards.

...

I live in Tennessee, where they are having a big "crack down" on opiates. I am worried that people like me will no longer be allowed to get pain medication. I can barely function with the amount of pain I have even with pain medicine. If I were to be completely cut off from it, I'm not sure I would be able to take it.

Can't be an active wife, mother or employee

I have two small children that need daily care. I have no help at home and peeing 30-60 times a day along with the pain makes me useless. Getting a good nights rest used to help but without pain medication I only sleep one to two hours before I need to pee. It is terrifying living like this. I have never felt so hopeless in my life.

...

I'm afraid I'm going to lose my job of 33 years because of the amount of work I'm missing due to pain and no pain meds.

...

It has affected my life in every way. I cannot work, or participate in the lives of my 5 perfect children. I am suffering so badly, and I'm very depressed.



QUALITY ALOE VERA PRODUCTS FOR IC/PBS

**Call 800-688-9977 for an info pack and
FREE sample of aloe vera capsules
100% natural relief with no side effects**

Read more about IC/PBS and our
double-blind, placebo-controlled clinical trial
at www.desertharvest.com
Click the Interstitial Cystitis link



Feature Story

When Bladder Treatments Don't Work

by Jill Heidi Osborne MA

If you had been diagnosed with IC/BPS forty years ago, odds are you would have been prescribed antibiotics, given urethral dilations and/or referred to a psychiatrist under the mistaken assumption that IC was all in your heads. Twenty years ago, that same patient might have been given harsh bladder instillations (i.e. chlorpactin, silver nitrate or DMSO) and/or Elmiron (approved in 1996). Ten years ago, they might have been given the IC diet, prescribed overactive bladder medications and perhaps given a trial of Interstim. But did they work? Did they really work? The answer, of course, is no, not for everyone. Even Elmiron & DMSO, the only FDA approved treatments for IC, have conflicting research studies and success rates. Why do some patients not respond to treatments?

The answer can be found in subtyping proposals now being debated and discussed by a variety of urology clinicians and researchers. The UPOINT/INPUT¹ subtyping system and Dr. Christopher Payne's five subtypes² help us to understand the nuance and clear variations found throughout the IC patient population. Subtyping focuses first on finding the specific pain generators (lesions, bladder, muscle, nerves, etc.) in patients so that the most effective treatments can be tried for their most unique case. If a patient is not getting better, revisiting the diagnosis and subtype is essential.

Hunner's Lesions

The first clear subtype of IC/BPS is **Hunner's lesions**. Lesions are now considered a separate and distinct disease process with biopsies rou-

tinely finding profound inflammation in the bladder wall. While these patients struggle with the most intense symptoms, the AUA suggested treatments (cauterization, laser or steroid injection) can cause remarkable improvement in pain, frequency and urgency. The new medical device LiRIS is also showing success at reducing the quantity and size of lesions, in some cases resolving them completely.³ Traditional bladder treatments (i.e. Elmiron, DMSO) are not considered effective however diet modification is essential.

Bladder Phenotype

The **Bladder Phenotype** includes those patients who struggle with a bladder wall dysfunction/trauma, such as that caused by chemotherapy, chemical exposure, excessive irritation from drinking coffees and other irritants. The classic symptom is pain or discomfort as the bladder fills with urine that is relieved by urination. Assuming that a UTI has been ruled out, treatments will focus on calming and soothing the bladder wall with diet modification therapies,

urinary analgesics/pain relievers (i.e. Azo Urinary Pain Relief tablets, Pyridium, etc.), bladder coatings and instillations. Botox and/or neuro-modulation may be helpful in more severe patients. This is the subtype that responds best to traditional bladder therapies. If simpler medications aren't working, it may be time to explore more aggressive treatments in Step Four & Five.

Myofascial Phenotype

The **Myofascial Phenotype** includes those patients whose symptoms are the result of tight, injured and/or dysfunctional pelvic floor muscles and/or fascia. This can occur after pelvic floor trauma, such as childbirth, pelvic injury, accidents, a history of repeated falls (i.e. ice skating, gymnastics, football). These patients may also have other orthopedic issues. The goal of therapy is to relax contracted, tight muscles and restore normal function and blood flow. Suggested treatments include stretching, yoga, myofascial physical therapy, muscle relaxants, pain management, trigger point work



and perhaps botox injection into muscle. Patients with PFD respond extremely well to pelvic floor physical therapy, muscle relaxation, perhaps trigger point or botox injections into the muscles. Bladder treatments might provide minor comfort but will not get to the root of the problem.

Pudendal Neuropathy Phenotype

Patients within the **Pudendal Neuropathy Phenotype** struggle with nerve dysfunction and/or entrapment. What makes these patients unique is that their symptoms are neurological in nature, including sharp, electrical type pain in the pelvis and/or urinary tract when sitting down. Some of these patients may struggle with PGAD, a painful arousal sensation due to compression or dysfunction of the pudendal nerve. Others may have been born with a birth defect that rerouted a nerve next to a bony structure that causes it to be compressed when sitting. Therapy is focused not only on calming nerves but finding the source of the nerve dysfunction through nerve blocks and, if possible, relief of any entrapments found. These patients are instructed to stop behaviors which result in pain, such as sitting for long periods of time. They may do yoga and or physical therapy to help relax tight muscles. Medications to calm nerves and control pain are impor-

tant. If these aren't successful, then nerve stimulation and/or surgical release of the entrapment may be necessary.

Central Sensitization/Systemic Pain Phenotype

The **Central Sensitization/Systemic Pain Phenotype** includes patients who struggle with other pain conditions such as IBS, fibromyalgia, vulvodynia, headache and/or allergies. Anxiety, depression and catastrophizing are common. These patients have signs of systemic (body wide) nerve sensitization, including sensitive skin, drug sensitivity, food sensitivity, an extremely sensitive sense of smell, chemical sensitivity and, of course, a sensitive bladder and bowel. They may also suffer with anxiety and depression. Treatment is focused on treating central sensitization, calming the nervous system and addressing and to help reduce/control any psychological symptoms. Would a bladder treatment address a systemic condition? No. Because these patients also struggle with bladder sensitivity, then the bladder phenotype self-help recommendations (i.e. diet modification) & treatments are also important.

In December 2017, the FDA's Bone, Reproductive and Urologic Drugs Advisory Committee is holding a meeting where they will be discussing the revision of criteria used in interstitial cystitis studies.

We can no longer blur the lines in patient recruitment for research studies. Clinical trials must sort patients more effectively based upon their subtype to ensure that new therapies are matched with the correct patient group.

Similarly, urologists, urogynecologists and primary care providers must step away from the "IC is a bladder disease" and "bladder treatments work for everyone" model. They must first identify the drivers of pain before suggesting treatments. Subtyping does this.

Lastly, patients must also understand that muscles and nerves can also trigger urinary frequency, urgency, pressure and/or pain. If you've been clinging to "my bladder hurts" whenever you flare and are using antibiotics or bladder wall treatments yet have not improved substantially, then it's time to look beyond the bladder.

References

1. Crane A, et al. Improving The Utility of Clinical Phenotyping in IC/PBS: From UPOINT to INPUT. *JUROL* April 2017 Volume 197, Issue 4, Supplement, Pages e386–e387
2. Payne CK. BPS/IC 2017: The Emperor Has No Clothes. 2017 AUA Annual Meeting Presentation. May 2017. Boston CA -
3. Peters K, et al. Safety, Tolerability and Preliminary Efficacy of LIRIS 400mg in Women With Ulcerative IC. AUA 2016 Abstract MP72-616

Consumer Alert - Warnings About Cipro

Be Cautious with Cipro and Other Fluoroquinolone Antibiotics

Now that flu and cold season is fast upon us, many patients have been sharing that they are again taking Cipro, a once popular fluoroquinolone antibiotic. Cipro is also often used for urinary tract infections. In 2016, the FDA issued an urgent safety warning about this class of antibiotics because of a high risk of permanent side effects, including: tendonitis, tendon rupture, muscle weakness and pain, joint pain and swelling, worsening of myasthenia gravis, peripheral neu-

ropathy (pins and needles in arms and legs), anxiety, depression, hallucinations, suicidal thoughts, confusion, skin rash, sunburn, abnormal, rapid or strong heartbeat and severe diarrhea. Side effects can occur hours or weeks after taking the medication and can last any average of 14 months to as long as 9 years after stopping the medication.

Healthcare professionals should not prescribe Cipro and other systemic fluoroquinolones to patients who have other treatment options for bacterial sinusitis, bronchitis and uncomplicated urinary tract infec-

tions "because the risk outweigh the benefits in these patients." Patients should contact their doctors immediately if they experience any serious side effects. The FDA suggests that treatment be stopped immediately and the patient switched to another class of antibiotic if there are any serious side effects.

Medications involved: Avelox (moxifloxacin), Cipro (ciprofloxacin), Factive (gemifloxacin), Levaquin (levofloxacin), ofloxacin.

Source: FDA.gov

The Latest IC Research

Study Receives Funding to Study Urinary Fungal Biome in IC Patients

Researchers at Cedars-Sinai Medical Center received \$350,000 in grant funding to study the microorganisms found in the urine of IC patients. Researchers in the NIH funded MAPP Network had previously discovered that IC patients struggling with flares often had the fungus, candida, in their urine as well as a significantly altered gut microbiome. This study expands that research by exploring the urinary bacterial and fungal flora in IC patients vs. controls. “We hypothesize that perturbations in this community of microorganisms may underlie or otherwise reflect IC/PBS symptoms.” If pathogens are found, they hope that this could lead to the development of new therapies and disease prevention strategies. They also hope to establish biomarkers based upon altered protein expression which could add in the development of new diagnostic methods.

Source: Ackerman, L. *The Urinary Fungal Mycobiome and Host Responses in Patients with Interstitial Cystitis*. PRMRP Discovery Award – Proposal: PR161914 - Award Number: W81XWH-17-1-0433

Real-Time Changes in Brain Activity During Sacral Neuromodulation for OAB

How does neuromodulation help frequency and urgency? Since its approval more than a decade ago, the operating assumption was that it was a local or regional effect... that nerves in the lower back and pelvis were being retrained to function normally. In a small study of 13 patients, six of whom completed the study, researchers at the Cleveland Clinic determined that an effect also occurred in the brain. Using magnetic resonance imaging, they found that sacral neuromodulation not only influenced brain activity but that the effect varied with the intensity of the

pubdental stimulation. The greater the stimulation, the greater the effect on the brain. Makes you go hmmm.

Source: Gill BC, et al. *Real-Time Changes in Brain Activity during Sacral Neuromodulation for Overactive Bladder*. *J Urol*. 2017 Dec;198(6):1379-1385.

Development of an IC Risk Score for Bladder Permeability

With hydrodistentions both expensive and painful, researchers have long sought to develop a non-invasive simple urine test which could identify patients with Hunner's lesions. Researchers at William Beaumont School of Medicine and Beaumont Hospital have developed a novel urine test which has reliably predicted the presence of lesions with 89% validity. The study collected 448 urine samples from 46 states consisting of 153 IC patients of which 54 had Hunner's lesions. They then measured urinary cytokines, small proteins involved in inflammation. (Hunner's lesions are distinct from all other subtypes of IC due to the presence of inflammation in biopsied bladder tissues.) An astonishing success, the authors conclude “The Bladder Permeability Defect Risk Score is the first validated urine biomarker assay for IC/BPS.” Very promising indeed! Let's see where this goes next.

Source: Lamb LE, et al. *Development of an interstitial cystitis risk score for bladder permeability*. *PLoS One*. 2017

Does Bladder Removal Reduce The Need For Opioid Prescriptions?

This study tracked narcotic medication use in 26 patients with the most severe bladder damage, “end stage” IC/BPS, who underwent bladder removal at Wake Forest Baptist Health between 2010 and 2017. They found that SOME but not all patients required less opiate pain medication after bladder

removal. In fact, 31% of these patients had stopped using opioid medication in the three months prior to study completion. This confirms that for a minority of patients, bladder removal can reduce pain. However, more than 65% continued to need pain therapy after bladder removal suggesting that their pain was coming from structures, nerves and/or muscles beyond the bladder.

There is no guarantee that having your bladder removed will eliminate your pain. A very careful diagnostic assessment of muscles and nerves, in addition to the bladder, must be performed before any considering of surgical treatment.

Source: Koslov DS, et al. *Impact of Cystectomy with Urinary Diversion upon Tracked Receipt of Opioid Prescriptions among Patients with Interstitial Cystitis/Bladder Pain Syndrome*. *Urology*. 2017 Nov 17.

Cross Organ Sensitization Between The Bowel & Bladder

Why do IC patients often struggle with IBS and other bowel related disorders? It turns out that the nervous systems of the bowel and the bladder share afferent nerves at the spinal cord. Researchers in Australia reviewed the literature showing that “cross-organ sensitization” occurs between the bowel and the bladder and that “in such circumstances, colonic inflammation may result in profound changes to the sensory pathways innervating the bladder, resulting in severe bladder dysfunction.” This suggests that a bowel trauma, illness, event could set the stage or be a triggering event for profound bladder dysfunction.

Source: Grundy L, et al. *Cross-organ sensitisation between the colon and bladder: To pee, or not to pee?* *Am J Physiol Gastrointest Liver Physiol*. 2017 Nov 16

Stem Cells Alleviated Inflammation And Inhibited Cell Death in IC

Researchers in China investigated the effect of human umbilical cord-derived mesenchymal stem cells (UC-MSC) when injected into rats who had their bladders damaged by cyclophosphamide. After one week of therapy with UC-MSC, bladder voiding improved, immunohistochemical analyses showed that the bladder cells were able to grow and repair damage, mast cells were reduced and inflammation improved. Stem cell therapy using fat derived stem cells has been studied in the USA with IC patients and the results were not long-term. It will be interesting to see where the Chinese take this line of research.

Source: Xie J, et al. *Umbilical cord-derived mesenchymal stem cells alleviated inflammation and inhibited apoptosis in interstitial cystitis via AKT/mTOR signaling pathway. Biochem Biophys Res Commun. 2017 Nov 11.*

Does The Urine of IC Patients Cause Cell Death?

Researchers in Spain exposed urine from IC patients on cell cultures and found a significant increase in cell death that intensified based upon the severity of an IC patient's symptoms. In contrast, patients with chronic pain did not show the same rates of cell death. The researchers conclude that this could be used as a marker for IC and as a way of contrasting IC patients from chronic pain patients. It was Susan Keay who, twenty years ago, discovered that the urine of some IC patients contained an anti-proliferative factor which appears to prevent cells from multiplying. Could it be related in some way? This study doesn't offer a theory as to why this might be happening nor does it provide a clear description of the subtypes used in the study (i.e. Patients with Hunner's lesions, etc.) but it is interesting.

Source: Di Capusa-Sacato C, et al. *Apoptotic effect as biomarker of disease, severity and follow-up in interstitial cystitis. Actas Urol Esp. 2017 Nov 10.*

Do IC Patients Have a Lot of Mast Cells in Their Bladder?

Researchers in Japan studied biopsy samples from 31 patients with Hunner's lesions, 38 patients without lesions, 19 patients with chronic cystitis and 18 with a normal bladder to determine if mast cell levels distinguished IC from other conditions. They found no significant differences in mast cell density among the four groups they studied and concluded that "mast cell count is of no value in the differential diagnosis of IC and other etiologies."

Source: Akiyama Y, et al. *Digital quantitative analysis of mast cell infiltration in interstitial cystitis. Neurourol Urodyn. 2017 Oct 24.*

Delayed Onset Ketamine Cystitis Case Study

Ketamine is well known for its ability to damage the bladder wall. Sadly, it has become a popular recreational drug throughout the world. About ten years ago, doctors began reporting on cases of ketamine cystitis with users showing often devastating damage to the bladder and kidneys. The damage and onset of symptoms was thought to occur within weeks or months of use which makes this study particularly interesting. Doctors in Barcelona Spain share the story of a 26 year old male who began struggling with urinary symptoms (pain with urination, frequency, urgency, incontinence, nocturia, hematuria and pain) at the age of 24. A urologist performed a cystoscopy which revealed lesions on the bladder wall similar to IC and common in ketamine users. When asked, the man said that he used 50mg of ketamine daily from the age of 15 to 17. This is the first case study to demonstrate symptoms onset years after ketamine use was stopped. The authors urge doctors to intervene with ketamine users before significant damage occurs.

Source: Robles-Martinez M, et al. *Delayed Urinary Symptoms Induced by Ketamine. J Psychoactive Drugs. 2017 Sep 21:1-4.*

Kenalog Injection Into Hunner's Lesions

Researchers at Drexel University Collect of Medicine (Philadelphia) evaluated kenalog injection as a treatment for Hunner's lesions in 100 patients who were treated over a 2.5 year period. They had a 1.1 decrease in pain at 12 weeks after treatment. Frequency decreased from 11.7 to 9.1 daily episodes. Nighttime voids decreased from 3 to 1.6. They conclude "The use of a corticosteroid may be beneficial to symptom control and improvement in the quality of life of interstitial cystitis/painful bladder syndrome patients."

Source: Rittenberg L, et al. *Kenalog Injection into Hunner's Lesions as a Treatment for Interstitial Cystitis/Bladder Pain Syndrome. Curr Urol. 2017 Aug;10(3):154-156.*

It's Time for a New Campaign Requesting More Public Toilets

If you plan on travelling to Amsterdam in the future, take note that there are only 3 public toilets for women in the center of Amsterdam as compared to 35 toilets for men. Out of desperation a woman had to urinate in public and was fined 90 euro's. The judge's comments were offensive. He said that she could have used a male toilet by climbing on top of a male urinal thus justifying the far fewer restrooms available for women. He also suggested that she should have urinated before going out. Would you, as a woman travelling in a foreign country, be comfortable walking into a male restroom? Wouldn't you be worried that you could be arrested? So much for women's rights. Appalling.

Case Study

An Unusual Cause of IC & Pelvic Pain Symptoms

A Urethral Diverticulum

by Jennifer Gonzalez MSN, APN, ACNS-BC
& Samuel Granpsas MD

(Editor's Note: The patient referenced in this case study contacted the IC Network earlier this year to share that after years of suffering with IC, a new medical team focused on one of her more subtle symptoms – urethral pain. With a simple MRI, they discovered that she was actually suffering from a large urethral diverticulum that extended the length of her urethra. With surgical removal, she is now pain and symptom free for the first time in years. We are grateful that her care providers have written up her story to share with other patients. Her case proves that it's not always the bladder or the muscles causing IC symptoms!)

As anyone who treats chronic pain knows, it is nearly impossible to completely resolve a patient's pain. For a provider, the complete resolution of a patient's pain is the ultimate experience, similar to the adrenaline rush following a game winning home run. Because of the complexities of pelvic pain, it is a difficult condition to treat and rarely does the patient have full resolution of symptoms. Our patients are desperately hoping that the next provider they see will be successful and knock the ball right out of the park. They want us to find an anatomic cause for their pain that can be treated with resolution of symptoms. This case study discusses the recent grand slam we hit in diagnosing and treating a urethral diverticulum with complete resolution in symptoms. This is not just to showcase one patient but to remind us that in many cases a pelvic MRI to diagnose urethral diverticuli or other subclinical abnormalities can lead to the elusive home

run for a patient with chronic pelvic pain.

The differential diagnosis of urethral pain is like any other. Often times, most conditions become obvious after a comprehensive history and simple testing such as a urinalysis and culture. In this case study, we look at a 53 year old female who presented to us seeking a local urologist for the treatment of her interstitial cystitis, pudendal neuralgia and persistent genital arousal disorder (PGAD). Her symptoms had been managed out of state with pudendal nerve blocks and botulinum toxin to the pelvic floor muscles every 3-4 months. In discussion with the patient, she had already had significant work up including cystoscopy, physical therapy evaluation and management, medication trials and treatment with an out of state gynecologist for

symptoms of pelvic floor tension myalgia leading to pudendal neuralgia and PGAD. She required very little of her local urologist save for refilling prescriptions and a referral to a local pelvic floor physical therapist. At the time of her initial presentation, our practice was small and we did not have a specialist in disorders of the pelvic floor. Our interstitial cystitis specialist was good, but had not experienced a patient with the significant pelvic floor abnormalities that were present in this patient. The patient was quite content with going forward with local pelvic floor physical therapy and traveling out of state for nerve blocks and botulinum toxin.

Our advanced practice providers (APP) do an excellent job at getting to know our patients. During a visit between botulinum toxin injections, the patient was talking to one of our advanced practice providers and



broke down telling her that her urethral pain never completely resolves with injections. At this time, the APP had completed training and was able to perform injections for the patient. On prior exams, there was no urethral abnormality present but while in clinic for injections, the APP noted a large, very tender urethral mass, but no purulence (pus) was able to be expressed. The patient was reluctant to have any testing done because she would be hesitant to have any pelvic floor reconstructive surgery and all prior testing was costly and always negative for any abnormality. With encouragement and persistence, an MRI of the pelvis was obtained and, to her surprise, our expectations were realized and a large horseshoe urethral diverticulum (a pocket or pouch extending away from the urethra) was discovered.

Urethral diverticulum

The incidence of urethral diverticulum in the literature varies. Smith's Urology reports the incidence to be between 0.6 and 5% (2008). It represents about 1% of the incontinent patients in a urology practice. At risk patients include those with traumatic vaginal delivery, perineal injury, previous pelvic surgery and sexual abuse. It is difficult to pinpoint as patients present with varying degrees of irritating voiding symptoms, recurrent UTI or the patient may be completely asymptomatic. Any patient who presents with the classic triad (dribbling, dyspareunia and dysuria) along with recurrent UTI should be worked up for a urethral diverticulum. Muddying the waters for diagnosis are those patients with long standing urethral syndrome, interstitial cystitis and pelvic floor tension myalgia as these patients have these complaints continuously. Diagnosis consists of a thorough history, complete exam and imaging studies. In 80% of patients a palpable urethral mass is present, however, this does not automatically indicate a urethral diverticulum. Differential diagnosis of urethral mass includes ectopic ureterocele, urethral carcinoma, vaginal wall inclusion cyst, Gartner's duct cyst, Skene's gland abscess, periurethral

fibroma, urethral varices, as well as other conditions (DeGrigorio, Lorge & Dupont, 2016). Endoscopy is seldom helpful because the openings are often very difficult to locate. In the past, retrograde and voiding urethrocytography but also retrograde urethrocytography with positive pressure tests (Riyach et al, 2014) have been used because this allows the urologist to participate in the interpretation. Though these can be performed, the gold standard diagnostic test when urethral diverticula are suspected has become the pelvic MRI (Tanagho & McAninch, 2008). Standard treatment consists of operative excision and reconstruction. The surgical interventions currently in use include transurethral marsupialization, open marsupialization, excision with reconstruction, and endoscopic unroofing (DeGrigorio, Lorge & Dupont, 2016). Surgical intervention has complications of fistula, urethral stenosis, urinary incontinence and lower urinary tract symptoms reported between 3 and 10% (Ryach et al, 2014).

The surgical approach used for our patient was an operative excision and reconstruction. The patient did not require a cystotomy (an incision into the bladder) and the surgeon, having performed many, reported that her excision was relatively easy. She had a catheter for ten days post operatively. There was concern that the patient would struggle with spasms and pain related to the catheter due to her reported history of Interstitial Cystitis. The patient did not report significant discomfort associated with the catheter although she did have a catheter associated urinary tract infection (*s. aureus*) that was treated with macrodantin for ten days. At the patient's one month follow up from surgery, her urethral pain had completely resolved. At the time of this writing, she has no symptoms of painful bladder syndrome, pudendal neuralgia, PGAD or urethritis and had weaned off of the tramadol she was taking for years. Currently, the plan is to wean the patient off of her chronic gabapentin as well.

After years of treatment for inter-

stitial cystitis, pudendal neuralgia, pelvic floor tension myalgia, and PGAD, this patient underwent a simple MRI of her pelvis which showed a large urethral diverticulum. The question now remains, was this patient misdiagnosed for all of these years? It is important to consider all possible pathologies for a patient who presents with pelvic pain and remember that interstitial cystitis is the presence of symptoms in the absence of identifiable pathology. In the past, misdiagnosis of urethral diverticulum was common. Any patient who presents with urethral pain and documented UTI should undergo a pelvic MRI if previous work up fails to provide a diagnosis. Only time will tell if our patient will present again with irritative voiding symptoms and pelvic pain. For the time being, we can relish in the fact that, at least for a while, we have successfully cured a chronic pain patient with complete elimination of pelvic pain. This has been possible by actively listening to our patient and having the knowledge of pelvic pain conditions. With this approach, maybe there is a "homerun" waiting to be scored in your pelvic pain patients.

Patient provided written consent to include case in publication.

References

1. Crescenze, I. & Goldman, H. (2015). Female urethral diverticulum: current diagnosis and management. *Current Urology Reports*. 16: 1. Retrieved online October 3, 2017 from <https://link.springer.com/article/10.1007%2Fs11934-015-0540-8>
2. Gregorio, M., Lorge, F., and Dupont, M. (2016). Female urethral diverticulum: diagnosis, treatment and outcome. Retrieved online October 3, 2017 from <https://www.omicsonline.org/open-access/female-urethral-diverticulum-diagnosis-treatment-and-outcome-2161-0932-1000374.php?aid=72315>
3. Riyach, O., Ahsaini, M., Fadl Tazi, M., Mellas, S., Stuurman-Wieringa, R., Khallouk, A., Jamal El Fassi, M., and Hassan Farihi, M. (2014). Female urethral diverticulum: cases report and literature. *Annals of Surgical Innovation and Research*. 8:1 Retrieved online October 3, 2017 from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3930819/>
4. Tanagho, E. & McAninch (2008) *Smith's General Urology*. 17th ed. McGraw Hill: New York

Self-Help Tip

How To Stop a Diet Induced Flare

by Jill Heidi Osborne MA



You couldn't resist. You had been so good. You avoided the cranberry sauce. Said no to the wine. You ate really well until dessert arrived. Grandma's irresistible chocolate cake started calling your name and wouldn't let go. Wanting to show her that you appreciated her cake (right?), you indulged and enjoyed every bite. Hours later your bladder starts to scream. If you're like most patients who are diet sensitive due to Hunner's lesions or a sensitive bladder wall, the holidays present with many opportunities to eat foods which later come back to haunt you with a wicked IC flare. If you've imbibed in a cocktail, enjoyed some cranberry sauce or fell for that slice of decadent chocolate cake, here are some strategies that you can use to nip this flare in the bud.

Bladder wall pain can be very sharp and shrill with some patients describing it as ground glass or razor blades in your bladder. Bladder wall flares may trigger intense frequency and urgency. A severe bladder wall flare can cause a false sense of fullness, as if your bladder is very full with urine even when it's fairly empty. It's important that you not try to strain to empty your bladder or get those last few drops out. Relax and let urination happen naturally.

Bladder Wall Flare Rescue Goals

- Dilute urine to reduce irritants
- Calm & sooth the bladder wall
- Prevent muscle tension from developing
- Fight pain early.

Bladder Wall Flare Rescue Strategies

First Hour

- Stop & Rest – Don't push through the pain
- Use a heating pad or take a hot bath or shower to relax muscles
- Drink a glass or two of water to dilute your urine. Your urine should be a pale, clear yellow. If it's dark yellow or brown, it is concentrated and more irritating. If it's clear, you're drinking too much water.
- Drink a soothing herbal tea, like chamomile or peppermint tea.

2 to 4 Hours – Get Serious About Symptoms (All of the above plus)

- If you've eaten something acidic, reduce your urine acid levels by using Prelief or Tums. You could also try 1/4 teaspoon of baking soda in a glass of water.
- Try a bladder analgesic to numb the bladder wall (i.e Azo Bladder Pain Relief Tablets). These are available at most drug store and supermarkets.
- OTC oral pain medications can help reduce mild to moderate pain such as ibuprofen (Advil) or acetaminophen (Tylenol). Do not take more than the recommended dosages. If used in large amounts, ibuprofen can cause stomach irritation while acetaminophen can irritate the liver.
- OTC supplements may have a calming effect - Desert Harvest Aloe, CystoProtek, Cysto Renew.

24 Hours or Longer (All of the above plus)

- Rescue instillations – If the flare has persisted, you can call your doctor and ask for a rescue instillation (aka – HepLidoA, heparin & lidocaine) to numb the bladder wall. Rescue instillations can be done at home if trained by your medical care providers. Some patients may use these daily until the symptoms calm while others may go to their urologist once a week for several weeks.
- Traditional treatments: Antihistamines (Vistaril, Atarax), Low Dose Antidepressant (Elavil), Bladder coating (Elmiron)

How long does a bladder wall flare last?

Bladder wall flares can be fairly short term. If the bladder is in good shape (i.e. IC symptoms are very mild), a cup of coffee (decaf please) might cause a few hours of increased symptoms, perhaps accompanied by an uncomfortable, sleepless night but the symptoms should resolve fairly quickly. On the other hand, patients who continue to drink coffee every day trigger cumulative irritation in the bladder that can extend bladder symptoms indefinitely.

With luck and early action, you've successfully nipped this flare in the bud!! Don't let IC diminish your holidays nor feel bad that you've eaten the wrong thing. We've all made that mistake and thankfully have some flare management tips that work!

ESSIC Meeting - Budapest Academy of Science Building Sept. 21-23

My Daughter's Journey with IC

by Gail Benshabat

(Editor's Note: Gail Benshabat has a mission to educate medical care providers that young patients who are struggling with IC and pain deserve their compassion and respect. The Canadian health care system failed her daughter. Primary care providers are poorly educated about IC and pelvic pain. It can take months or years before patients see an IC expert. Treatment options are limited. Like most other countries, patients in pain struggle to find doctors who believe them. We paid for Gail to attend the ESSIC meeting in Prague to share her daughter Lisa's story with providers from around the world. Her speech is difficult to read but important to hear. With the newly proposed subtyping systems under study, we now have far more hope. Patients are now receiving treatments for their specific presentation of IC and, as Dr. Christopher Payne said, cure is possible for some subtypes. However, we do face an uphill battle with respect to pain care that requires our collective voices. Every patient deserves hope that Lisa, tragically, was never given.)

Hello and welcome everyone. What you are about to hear is an emotional account of a young woman named Lisa Benshabat – my daughter and her journey with Interstitial Cystitis. My goal is to put a face to Interstitial Cystitis (BPS) so that more people will understand how serious this chronic disorder really is and how it touches so many lives around the world. This presentation will reinforce how dire the need is for emotional support for the individual, as well as for family members. There is an urgent need to work together, to educate, research and find ways to help patients not feel so isolated.



Lisa - growing up

This lovely young girl you see in front of you is a healthy and happy young twelve-year-old Lisa. She was full of life and energy. She loved school, her friends, music, being around her sister and family. Lisa had one of those contagious smiles that would light up a room. She had an innate sense of positivity, often finding humour in so many things. This was a girl who had an affinity towards animals, brimming with compassion and love.

In time, Lisa had dreams of going to university, dating, working with animals or children, travelling, furthering her love of guitar and art. She thought about becoming a teacher. This is a girl who wanted to save the children in Africa by selling her art on T-shirts. She had strong aspirations of making a difference in the lives of those less fortunate.

Lisa loved working with children and they loved her gentle demeanour. In her late teens, she decided to become an early childhood educator. In her early 20s, she volunteered at a local daycare, where a co-worker later revealed the essence of who she really was as a person. Unabashedly, he said “Lisa,

you remind me of a present – every time you open it up, it keeps getting better and better.” Everyone who knew Lisa saw her as a warm-hearted, non-judgmental person, always giving so much of herself to others.

Medical Maze

When Lisa was only 12 years old, she came to me and said “Mom, it really hurts after I pee. Something's not right!” At first I thought it was a UTI or bladder infection. Little did anyone know that this would be the beginning of something much more complicated. In fact, this marked the beginning of Lisa's journey with IC.

Lisa couldn't articulate what she was going through. As Lisa's mother, her symptoms were worrisome. The merry-go-round of tests and doctors began with a simple blood test. Some bacteria were detected in her urine, but antibiotics didn't help. She continued to experience ongoing symptoms of pain and pressure. IC was an “invisible thief.” Doctors were unable to find a thing wrong with her. Not a thread of evidence. The pain continued. The symptoms were persistent, but no-one could “see” what she was “feeling.” It raised the question: “What could possibly be causing such a drastic shift in her previously normal

peeing habits?”

A month passed until Lisa was able to see a urologist who performed a cysto with distension. Following the procedure, the doctor casually muttered, “She’s got **BORDERLINE INTERSTITIAL CYSTITIS.**” What exactly did that mean? I had no clue. There was no discussion, no explanation and no literature handed to me. Nothing! I had to do my own research. As it turned out, Lisa was lucky. The medication she was prescribed seemed to have relieved some of her discomfort. She went back to school. Was she really better? Unfortunately, not. During her elementary and high school years, she hid her pain. The symptoms she experienced when she was 12 were never really “gone.” It was like a volcano ready to erupt. It was just a question of when. She continued to have off and on bladder pain, spasms and urethral pain – but being a trooper, she did her best to ignore the symptoms.

By the age of 19, Lisa experienced a severe bladder infection. She described her symptoms like this: “*It feels like I’m peeing razor blades. I constantly feel the need to pee. It hurts when my bladder fills and it hurts when my bladder empties.*” The pain became so severe, she could hardly get up to go to the washroom. It hit her with a vengeance. Any movements – walking, standing, sitting down, climbing stairs were all, in Lisa’s words “*torture.*” On a daily basis it felt like a bowling ball sitting at the base of her bladder – a constant pressure feeling that wouldn’t go away. There was little to no relief after voiding. After the infection was cleared, she was never the same. It was one roller-coaster ride of pain ups and downs followed by more doctor referrals that went on for the next 7 years. No one could give us any clear answers.

During this time we resorted to becoming our own “scientists,” researching, turning to ‘Dr. Google,’ documenting symptoms and reaching out to IC support groups, experimenting with different medications, trying teas and special diets. We were anxiously trying to put the pieces together on our own. All this time,

we received a lot of help from support groups, the first being the IC Network. They were our lifeline.

Lisa thought IC was a rare disease, however after going online, she discovered that there are millions of people who have IC. She often remarked how IC is not really treatable and that symptoms could only be managed. It bothered her that so few people cared to understand it. I started to think about that. How could a disease, more common than we think, be so misunderstood?

Friends and isolation

Lisa loved being with her friends and doing all the things that young people like to do together. But, when she was in pain, she couldn’t make plans. So few friends really understood that part of her suffering. And when it happened constantly, friends and family just assumed she wouldn’t join them. So few friends understood how this condition can cause depression, anxiety and sleep deprivation. From high school years right through to her 27th birthday, Lisa fought her pain in silence, opening up to only a few close friends. She had urethral spasms, frequency and intermittent pain in her bladder. There were days, sometimes weeks when she was okay and then there were days when she just wanted to curl up in a ball and stay in bed all day. She badly wanted to go out with her friends, meet new people and go out on a date. But she saw that sense of “normal” slipping away. IC affected every aspect of her life – from wanting to work, study and socialize. It affected her physically, mentally and emotionally - nothing remained untouched.

What pain does to you

Pain...it’s a strange thing. It does things that changes your thinking. It quite literally rips you apart physically, emotionally and psychologically. Pain is trauma to the body and after a long long time, it wears you down. That’s a fact. It isolates you. It makes you feel helpless and useless. You desperately want someone to say “*There is hope. There is a way to manage this.*” But that never happened for Lisa. It doesn’t happen for a lot of people. Many of her doctors

said “*I’m sorry, I can’t help you. You’ll just have to live with this.*” She didn’t hear one word of encouragement. She didn’t hear what she needed to hear: “*I believe your pain is real. I hear you. You will get through this.*” No one gave her hope, outside of her family.

“All in your head”

By Lisa’s 26th birthday she had seen the inside of more than 10 specialists’ offices across N.A. – and NOT ONE doctor could shed a bit of light on her ongoing physical pain. By this time she had seen numerous specialists, neurologists, pain specialists, physiotherapists and an acupuncturist. She was even told to see a psychiatrist because by this time doctors were alluding that her symptoms were “all in her head.” But Lisa knew better. “*How could doctors think for one moment that my mind is making all of this up?*” she would say. By this time, she was reaching her breaking point. A young woman with dreams and aspirations of literally wanting to save the world, and no-one could save her. No-one knew enough about IC. After countless tests (echo-cardiographs, CATScan, uro-dynamics, ultra-sound, etc.) – everything came back normal. Even the second cysto came back normal! What happened to “borderline I.C.?” By this time, Lisa was starting to give up hope of every getting her life back.

Definitive diagnosis

In 2014, Lisa was referred to a doctor outside of Toronto – an IC Specialist who performed a battery of tests. I can’t even begin to describe the feeling we both felt when we got an appointment with an actual IC specialist. Before all of this, it was like finding a needle in a haystack. Imagine, so few doctors knew anything about IC and yet so many people were suffering, horribly. Finally, after years of unrelenting pain, Lisa received a definitive diagnosis. Our hunch was right. It was IC. A few treatment options were presented, such as bladder instillations and Elmiron. Lisa decided to try Elmiron first, as well as add Amitriptyline for pain management. It was beginning to feel like a craps shoot. Everything was trial and error.

Wanting to feel normal

On most appointments her pain specialist would remark, (with full optimism) “*You look great Lisa!*” There’s no denying it – she always “looked good” but inside she was suffering. In reality she didn’t feel the way other people feel. I can never forget her words that were repeated over and over again – “*Mom I just want to feel normal. . . Please. . . doctors have to know what I’m going through. . . what other people must be going through..*”

In the fall of 2015, Lisa was willing to try anything. She was barely able to finish her studies in Early Childhood Education. She succeeded in finishing everything except a field placement. There were days when she felt okay and other days not. Everything revolved around her level of pain.

Some ups and downs

Grasping at straws, she focused more on her diet, switched to another medication, and started following the AUA protocol for managing IC. The first line of defence: Physiotherapy, pain management, diet and stress reduction techniques. The “real” game-changer was “diet.” Her Naturopathic doctor put her on a more holistic path – focusing on known allergens and eliminating them from her diet. Believe it or not, it made a significant difference in her pain level. Things were actually looking up!

Losing Hope - 2016

By early 2016, Lisa knew that that this was going to be an uphill battle, no matter how she looked at it. After 16 years of going in a vicious circle, she had enough. She was tired and drained. On February 9, 2016, at 3:45 p.m. I came home and found my daughter’s lifeless body. She had taken her life. “*Mom. . . “I want you to know that you did everything you could to help me and more. . . I couldn’t have gotten this far in life without your endless love and support. At this point I can tell you that I lost hope that I would ever get better.”*”

IC Patients - Resilience

I have to stop here a moment and tell you. . . Lisa and many others like her had who could not continue along this path, had resilience. They fought and they fought hard. It makes me think – how many lives

could we have saved if the medical professionals had asked the right questions, intervened at the right time, pooled their knowledge with others and really listened to their patients’ stories.

Suicide - sometimes a last resort

It’s not uncommon for women (and men) with marginalized conditions like IC to feel hopeless, even suicidal. Women with chronic pain attempt suicide 4 times more than the general population. Suicidal ideation is 3 to 4 times higher in IC sufferers. No-one wants to opt for suicide, but when the physical and mental anguish become too unbearable, for some people it becomes the only way out. I hope this changes.

Final thoughts...

As a mom, I needed to search for different pathways to understand the disease. Not just for Lisa but for the millions of people who are seeking answers. Some of those answers came from support groups from around the world – people who have done their research and took on IC as a life-long research project – reaching out to IC sufferers. IC, like many other marginalized diseases gets a real kicker. Why? IC disproportionately affects females. You see, if you’re a female, you’re told that you exaggerate your symptoms and if you’re a male, you’re told to be strong and face up to it. This is one of the things that we need to change.

There’s been a stark rise in autoimmune disorders over the past 50 years, from Type 1 diabetes and Multiple Sclerosis to asthma and Celiac disease. Fortunately, we’re slowly starting to understand what affects our immune system: food, environment and toxins are definite triggers. If we’re going combat these diseases, we have to work together. We have to collaborate and share information across all disciplines.

As a mother, my first instinct is to protect my children. You see, I had to be strong and convince my daughter that she she would get better, even though doctors weren’t giving us a lot of hope. All too often I would turn my eyes away from the sobering facts: Approximately 50% of IC patients can’t hold a full-time job. Many have a quality of life that resembles that of person suffering

from cancer. Most people can’t comprehend what it’s like to live in pain because the outside doesn’t show what the person is suffering inside.

Despite everything, I still have hope. My daughter’s journey, that spanned 16 years opened my eyes to some beautiful things. It has taught me something about pain through the lens of empathy. I don’t have pain but I can honestly tell people “*I know what you’re going through and will fight with you AND I will fight for you. I will take you seriously.*” I’m grateful for what is being done by E.S.S.I.C. and by those who are researching new ways to understand IC. I encourage more people to take the path less travelled. If we ask the right questions, imagine what we can accomplish.

Special Thanks

I want to thank the IC Network and Jill Osborne (President and Founder) who so graciously covered my travel expense to the ESSIC meeting here in beautiful Budapest. Her knowledge and expertise on IC has given me the strength to keep going and advocate for others who are losing hope.

Thank you to the Four Seasons Hotel – Gresham Palace for providing accommodation during the E.S.S.I.C. Meeting. I am so appreciative of their generosity.

Thank you Dr. Wyndaele and Dr. Lovasz, as well as the ESSIC Committee members who allowed me to be here today. It has truly been an honor and a privilege to speak, not only on behalf of my daughter but for all IC patients. This has been an incredibly humbling experience, to be here and to carry on Lisa’s legacy by bringing awareness to IC. I know, in my heart, she would be so proud. Thank you.

September is IC Awareness Month. This is a time when IC patients and advocates all around the world raise awareness about interstitial cystitis. But let’s not stop here. We can all make a difference if we do our part. I urge you to write about IC/IBS, share your information and stories and spread the word to your social networking community, your government representatives and media outlets so that we can all make a difference in the lives of those living with IC/IBS.

How to Qualify for Disability Benefits with Interstitial Cystitis

by Bryan Mac Murray, Disability Benefits Help

As of November 2002, the Social Security Administration (SSA) determined that critical cases of interstitial cystitis may be a basis for finding disability, allowing those with severe diagnoses to finally receive the help they deserve. If you or a loved one is unable to work or live their normal lives because of their IC, then Social Security disability benefits may be an option. Continue below to learn how to qualify.

Two Programs

It is important to understand what Social Security disability benefits are, the different programs available, and how you can meet their technical qualifications. Depending on your work history and current income, you may qualify for one (or both) of two different Social Security programs: SSDI and SSI.

- **SSDI (Social Security Disability Insurance)** is for those with a past work history. Applicants qualify for this program if they have contributed enough “credits” (money in taxes) to Social Security in their lifetime. More credits are required of people who are older, as they have had more time to work and pay taxes. For example, a 39-year-old needs 20 credits (or 5 full years of qualifying work) to be eligible for SSDI, while a 58-year-old needs 36 credits (9 full years of work) instead. Those who receive SSDI qualify for monthly financial benefits and Medicare insurance.

- **SSI (Supplemental Security Income)** is a program for those who are unemployed, do not have a work history, have low income, or who are under 18. It does not require appli-

cants to have contributed credits to Social Security, but it does require that their income is low enough to demonstrate financial need. To qualify, applicants must make under a certain amount of money each month. The current income limits for SSI applicants is \$735 for a single applicant or \$1,103 for a couple. However, applicants with certain kinds of unearned income may still qualify for benefits while making more than this.

SSDI (Social Security Disability Insurance) is for those with a past work history. SSI (Supplemental Security Income) is a program for those who are unemployed, do not have a work history, have low income, or who are under 18.

If you are unsure whether or not you qualify for a program, you can use the SSA’s online income calculator or speak with a representative at your local Social Security office for help. (www.ssa.gov)

Medical Requirements

When the SSA evaluates disability applications, they compare an applicant’s diagnosis to its matching entry in the “Blue Book”. This book con-

tains entries for all SSA-approved disabilities, as well as the evidence required for applicants to demonstrate their disorder’s severity. The reason that most diagnoses also require supporting evidence is for the SSA to ensure you are “totally and permanently disabled”. This term means that your disability is severe enough, and will last long enough, to keep you from working or functioning normally.

Because receiving benefits for interstitial cystitis is still rather rare, it currently does not have its own listing in the Blue Book. However, this does not mean you are ineligible to qualify. Applicants can medically qualify with IC in two different ways:

- **Qualifying under a separate listing.** If your IC symptoms qualify you under another disorder’s Blue Book listing, then you may be eligible for benefits this way. For instance, chronic and severe IC is known to be linked with high levels of stress and depression. If this is the case, your IC may qualify you under section 12.04 of the Blue Book which handles severe mental health disorders.

- **Qualifying for a medical vocational allowance (MVA).** These are reserved for people whose disabilities are not listed in the Blue Book, but who qualify as disabled enough to be incapable of doing any work they are qualified to do. For example, if a person spent their life in trade school learning to be a mechanic, but is unable to continue the only work they were trained for because of their IC, then they may qualify for an MVA.

Regardless of how you qualify, it is

important to provide the SSA with any and all documents demonstrating the severity of your IC. From medical records, test results, and hospitalization history to pay stubs and coworker testimonies, it is always best to provide more information than less.

Applying for Benefits

Applications for SSDI can be started online whenever you are ready. The application can be found on the SSA's main website along with FAQs, paperwork checklists, and many other helpful resources.

Applications for SSI are currently unavailable online and must be made in person via an appointment at your local Social Security office. However, you can choose to begin the process online by filling out an Online Application for Disability Benefits. This will help gauge your eligibility as well as give you the option to transfer the information to your in-person application.

What To Do If You've Been Denied Benefits

If you've been denied benefits, there is an appeals framework in place to ask for reconsideration of your case. Many applications based on interstitial cystitis are denied because Social Security may not attempt to obtain a statement from a treating physician at the initial application level. In addition, you may not have the chance to describe how your IC reduces your ability to work.

The next stage of the appeals process is Reconsideration. At this stage, you can submit new evidence about your case, however it has the same issue as the initial application – you may not be able to make a case based on the evidence that the SSA reviews.

If you file for the next stage, a hearing before an administrative law judge, you may be able to make an effective case with statements from a physician, in addition to a vocational expert.

Regardless of what stage of the appeals process you are in, you have the right to be represented by an attorney or disability advocate. If you've been denied, it might be a good idea to reach out to one in your area to get a better idea as to how to appeal your case.

This article was written by the Outreach Team at Disability Benefits Help. They provide information about disability benefits and the application process. To learn more, please visit their website at <http://www.disability-benefits-help.org> or by contacting them at help@ssd-help.org.



Prelief
Dietary Supplement

Do acidic foods and drinks bother you?

PRELIEF CAN HELP

www.prelief.com

Santa Rosa Fire Update

ICN Back Open for Business

by Jill Heidi Osborne MA

If you've been following the ICN social networking channels this Fall then you know that we were in the center of the Northern California fire storms in October. Evacuated, I had no choice but to close the ICN for several weeks. Cleanup has just begun as thousands of homes and businesses try to pick up the pieces and rebuild their lives. Here's what happened.

On Sunday October 8th, we were in the middle of a week long "Red Flag" warning for forest fires. The weather had been hot for weeks, the grass on the hillsides were brown, bone dry and high inland winds (50 to 80mph gusts) were anticipated. By the time I went to bed around 10PM, the winds were whipping branches against my bedroom window and there was a hint of smoke in the air. Transformers had been blown out and power lines had gone down, setting off several small but easily controlled fires throughout the North Bay.

Ten miles north of us, near the town of Calistoga, another fire began that quickly expanded south. Moving at an estimated football field every three seconds, it took just two hours to move into the hills above my home and city (Santa Rosa), leaving carnage in its wake. By the time my 95 year old father woke me up at 1:30AM, the skies had turned red and the air was so thick with smoke that it smelled like gunpowder. Cars and trucks were fleeing southward down from the hills.

That night more than 5,000 homes burned. It raced down a beautiful agricultural belt (Mark West) burning farms, vineyards and ranches. It travelled up and over the



Fountaingrove neighborhood where residents, many seniors, had no clue that their lives were in danger. One of our family friends, an elderly woman, ran for her life leaving her pets and horse behind. They did not survive. The chairman of our local hospital and her husband ran in their pajamas down the street, unable to get their car out of their garage. They had no time to even grab wallets and purses. Several elderly residents died in their homes, their garages or their cars because they could not move quickly enough to get out.

The fire then raced down the hillsides into the city itself, where it licked the walls of two major hospitals, forcing their evacuation. It jumped a four lane freeway, burning several businesses before racing into yet another large neighborhood, Coffey Park, leveling thousands of homes. One of my good friends was on the phone with her daughter when her daughter screamed that her house was on fire. The line went dead. It took Julie three terror filled hours before she was able to connect with her children again. They, too, fled with nothing but their pets and wallets. My friend Melissa, pregnant with her first child, welcomed two of her friends who had evacuated from the Mark West area. They ALL had to flee her Coffey Park home an hour

later. They were able to get out with their pets and computers.

This fire had no preferences. It struck the rich and the poor. It burned schools, hotels, medical offices and assisted living centers. Simply put, it was a nightmare from which we are still recovering.

Thankfully, my home did not burn but it came close. Our first evacuation lasted five days. We returned, cleaned out the fridge, bought \$200 of food and at 4:30AM the next morning the police arrived with sirens and loudspeakers telling us to run. A new fire was approaching from the east and we could see the flames. This time we had 15 minutes to get out. Terrifying? You better believe it.

Now weeks later, the fires are finally out but we are all struggling with disaster fatigue. Everywhere we go, every single day, we see homes burned and family members picking through the wreckage looking for a few family treasures. At the store, the doctor or the movies, everyone talks about what they've lost or what they experienced. Hundreds of notices for lost pets are stapled throughout the city. Men and women, myself included, cried freely for weeks. There's not just a physical recovery to be had, but also an emotional recovery. I expect that it will take many

months or years before that happens.

I would like to thank everyone who reached out with offers of a safe place to stay, as well as their support and encouragement. Thank you also for your patience. We had a TON of messages on our phones but without power, internet and cell service we couldn't access those messages and return those calls.

I would like to thank Heather Brown, our newest ICN Shop employee, who came to work to our warehouse everyday and literally kept the orders going out the door. She, too, had to evacuate but still came to work. AMAZING!

Thanks to Janice and Brian Schmidt, my sister and brother in law, who offered us sanctuary and took my frantic desperate phone calls as we tried to decide what to do. Angels all!

Here are some of my lessons learned about evacuating quickly -

- Always keep a few cases of water in your garage and/or car. We went through several cases of water during our evacuation.

- When the power goes out, credit cards cannot be used. Disasters create a cash and carry economy. Always have some cash on hand in case of emergencies. We went through about \$1000 for gasoline, food and supplies for four people.

- Fill up your car when it hits half a tank. That first night, I had about 1/8th of a tank of gas in my car and with the power out, there were no gas stations open. Worse, I couldn't drive around looking for gas knowing that I might need to evacuate 50 miles away. Thankfully, a neighbor gave me a few gallons of gas. I'll NEVER let that happen again.

- Keep your essential medications in one spot, preferably an easy to carry bag or box so that you can grab them and run.

- Check on your neighbors! Bang on doors if you must. One young man banged on 100 doors in the Coffey Park neighborhood, a true hero.

- Sign up for Nixle Alerts on your cell phone so that you can receive warnings about disasters or emergencies in your community. Evacuations

were first announced through the Nixle System.

- Have a portable radio available (aka the old transistor radios) so that you can listen to the local news when your phones are down.

- Remember that seniors may not hear sirens or own cell phones. They also cannot move quickly. Please check on them in your neighborhood.

- If you know of residents who are disabled or in wheelchairs, please help them evacuate and/or call 911 to get them out.

- Don't leave pets behind unless you are forced to. Our evacuation centers allowed animals to be brought with them. Our local fairgrounds took in lots of horses, cows, goats and so forth. If you have a lot of small household pets, make sure that you have the ability to move them quickly and easily, preferably with crates. Cats can be evacuated in pillow cases!

- Keep in touch with your single friends who are facing disaster alone. They often feel alone, isolated and scared. Bring them into your homes if you can.

Clinical Trial Announcements

The Leadership 301 Trial Seeks Men & Women In USA, Canada & Europe

It is estimated that approximately 4% (25 million) of the adult population in the US and in Europe* may experience Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS) symptoms. If you or someone close to you has IC/BPS, you know how challenging it can be to live with its symptoms of ongoing bladder pain, urinary frequency (needing to go often), urgency (feeling a strong need to go), and/or pressure or discomfort in the bladder/pelvic area.

Study Purpose

The Leadership 301 Trial is evaluating an investigational drug (AQX-1125) to see if it will reduce bladder pain and relieve other symptoms such as urinary frequency. The investigational drug is a new type of medication that may help reduce inflammation in the bladder. In an earlier study in women with IC/BPS, those who took the study drug every day for six weeks experienced reduced

bladder pain and improved symptoms compared to those who took placebo.

Eligibility

You may qualify if you:

- Are male or female between the ages of 18 and 80 years
- Have been diagnosed with IC/BPS for at least 3 months but less than 20 years
- Have consistently experienced moderate to severe bladder pain, urinary urgency, and/or urinary frequency

What Will Happen During the Study

As a study participant, you will have regular contact with the study team who will monitor your health closely. There will be 13-14 visits during the study, which will last approximately 22 months. There will be a 12-week treatment period and a 52-week extension. During the treatment period there will be a 1 in 3 chance you will receive placebo. After completing the treatment period, you will be randomized into an

extension period where all patients receive active study drug. There will be a final follow-up visit 6 months after the last dose of study drug.

Study Locations

- **USA** - Alabama, Arizona, California, Connecticut, Georgia, Indiana, Iowa, Louisiana, Maryland, Massachusetts, Michigan, Nevada, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, South Carolina, Tennessee, Texas, Virginia, Washington, Wisconsin

- **Canada** - British Columbia, Ontario, Quebec

- **Europe** - Belgium, Czech Republic, Denmark, Hungary, Latvia, Netherlands, Poland, Romania, Spain, United Kingdom

Additional Information

To learn more about the Leadership 301 Trial and to find a participating study site close to you, visit <http://www.leadership301.com>

The IC Diet Project **Simple and Savory Holiday Dishes**

by Bev Laumann



I don't know about you, but this last week before the holidays is usually a mixture of excitement, busy-ness, nostalgia, and fun...with a bit of anxiety thrown in for flavor. I usually want everything to be perfect: the perfect presents, the perfect gatherings, and the perfect food, all to help create the perfect memories.

But think about it. What do you remember about the holidays of your past? Is it the meticulously decorated tree? Is it a turkey roasted to the perfect golden brown? Or is it the people and the songs and the laughter and the joy of just being with those you love?

One of MY favorite Christmas memories was the year we all had the flu in my house. How could that be, you wonder? Well, it was the first year my husband and I stayed home with our three young children (9, 6, and 4 years old) without running around visiting. We stayed in our pajamas all day, and each person found a place to lounge curled up in a blanket. We didn't experience the chaos and squeals of other Christmas

mornings, instead we opened packages slowly...very slowly. I truly believe that one of the "benefits" of not feeling 100% was that we savored the joy of each gift. In fact, half-way through the day we all stopped and worked on a 3-D puzzle. To this day I can visualize that puzzle on our coffee table; each person taking a turn putting in a piece until it was complete.

Since we had planned to eat at someone else's house that year and couldn't, I threw together a frozen roast beef, potatoes, carrots, onions, and celery and let the slow cooker gradually fill the house with the deliciousness of a wholesome, every day, family meal. And yes, we stayed in our pajamas to eat. We liked this so much that in the years to come we deliberately stayed in our pajamas all day and had roast beef as our meal.

What fascinates me most, however, is when I look back at 35 years of holidays as a wife and mother, it is that perfectly imperfect Christmas that has the most vivid memories. Imagine that. Things didn't have to be perfect to create the

best memories. So as you are scurrying around trying to pull together your last minute preparations, remember to prioritize your efforts. Don't be afraid to take a few shortcuts to save your energy for what matters most – your most cherished traditions and your family and friends.

Holiday Food Shortcuts

As much as we look forward to our holiday meals, the preparation can be time consuming and stressful. Here are a few shortcuts that can help you still enjoy holiday favorites while conserving your precious energy for your family, friends, and yourself!

1. Plan meals where people can personalize their dishes. With enough variety, everyone can choose the foods they like and avoid their personal food sensitivities. For example, set out platters of meat, cheese, vegetables, and spreads with wraps and buns and let people make their own sandwiches. Bake large restaurant size potatoes and set up a topping bar with cheeses, vegetables,

salsa, beans, and chopped meats (chicken and bacon are common choices). Ice cream sundae parties are also fun! Don't forget to include holiday flavors like gingerbread cookies, crushed candy canes, and cookie sprinkles.

2. Purchase plain, cut sugar cookies: Order from a local bakery and decorate them at home. Take extras to nursing homes, the fire station, shelters, or neighbors.

3. Use frozen prepared pastry shells for your pies: Bladder and stomach friendly pies like custard, banana cream, coconut cream, apple, butterscotch, pumpkin, and sweet potato pies are easy to make! You can also use these frozen crusts for quiche or make meat pot pies out of left-overs.

4. Add a little holiday flash to everyday foods: Add some cookie sprinkles to pancake dough. Garnish plates with a slice of orange and a sprig of parsley. Crumble a simple streusel topping (brown sugar, partially softened butter, cinnamon, and flour) on blueberry muffins before you bake them. For a fun party mix, drizzle melted white chocolate over bagged caramel corn and roasted almonds that you have spread on cookie sheets – add some candy sprinkles before the chocolate hardens. Break apart and serve in pretty holiday pans or dishes.

5. Collect leftovers in one bowl/bag and put in your freezer. Small portions of leftover peas, carrots, corn, rice, and meat can be thrown in a slow cooker to make a great stew or soup.

6. Clean up as you cook. Keep a garbage can nearby and load and unload the dishwasher as you go. Use antibacterial kitchen wipes to give your cooking surfaces a once over when you are done.

Spinach and Feta Quiche

(From Confident Choices® A Cookbook for IC and OAB)

Looking for a quick but special holiday breakfast? Prepare this simple, savory quiche ahead. Pop in the oven when you are opening packages and soon the smells of breakfast will fill the



house! Serve with fresh berries making Christmas morning savory, simple, and special!

Ingredients:

- 2 (10 oz.) pkg. frozen chopped spinach (thawed)
- 5 eggs
- 1 c. half and half (may substitute 1 c. evaporated skim milk)
- 1 c. crumbled feta cheese (4 oz.)
- 2 T. chopped green onions
- 1/2 t. lemon zest, if tolerated
- 1/2 t. salt
- 1/4 t. pepper
- 1 unbaked, frozen deep-dish 9-inch pie shell (I like Marie Callender's brand)

Directions:

Pierce bottom of pie shell and bake for 5 minutes at 350°F. Cool slightly. Raise temperature of oven to 400°F. Drain spinach and press out all liquid. (This can be done easily between layers of paper towels.) Set aside.

Whisk eggs and half-and-half or milk in bowl. Add cheese, green onions, lemon zest, salt, and pepper. Pour into partially baked pie shell. Bake on middle rack, 400°F for 10 minutes, reducing oven temperature to 350°F for the last 25 minutes.

Broccoli and Cheddar Quiche: Substitute 1 cup frozen broccoli florets for the spinach and 1/2 cup

shredded white cheddar cheese for the feta cheese.

Slow Cooker Beef Stew

Sometimes having an elaborate Turkey Dinner just isn't possible. A simpler meal, such as Beef Stew, is easier to make, adds less stress to the day for the cook in the family and can provide a lovely family feast. Pair it with your favorite hot biscuits, corn-bread or rolls. Serve with a salad of your choice and enjoy!

Ingredients:

- 2 lbs. beef chuck
- 1 t. paprika
- 1 1/2 t. salt
- 1/2 t. pepper
- 1/3 cup all purpose flour
- 3 T olive oil or shortening
- 1 medium white onion (if tolerated), sliced thinly
- 1 clove garlic, chopped
- 1/2 pound small mushrooms whole or cut in halves
- 1 pound small white potatoes, cut into quarters
- 1/2 package baby cut organic carrots
- 2-3 cups organic beef broth, low salt (no msg please)
- fresh thyme springs

Directions:

Cut beef into bite size pieces. Toss with paprika, salt and pepper and flour, the shake off excess flour. Heat oil to medium high in your slow cooker and brown meat. Cook until browned on all sides. Add in sliced onions, chopped garlic, carrots, mushrooms and potatoes and continue to saute for five minutes. Add two to three cups of beef broth and fresh thyme. Simmer on low for 6-8 hours or until meat and veggies are tender. If you would prefer a gravy like sauce, remove 1/2 cup of sauce from the slow cooker. Stir (or whisk) in 1/4 cup flour into the 1/2 cup sauce until no clumps remain. Stir back into the slow cooker and cook for an additional five or ten minutes until the sauce thickens.



Butterscotch Pie

(From Confident Choices® A Cookbook for IC and OAB)

If you love the caramel goodness of butterscotch, here's a special holiday pie recipe with a rich Southern flavor.

Ingredients:

- 2 T butter
- 1 c. brown sugar
- 2/3 c. hot water
- 2 T flour
- 3 T cornstarch
- 1/2 t. salt
- 2 egg yolks
- 2 c. milk
- 1 t. vanilla
- 9-inch baked pie shell (can use baked from frozen prepared shell) or small pie shells
- Meringue

Directions:

Brown the butter in a heavy saucepan over medium heat; add the brown sugar and stir it until melted. Add the hot water and cook, stirring syrup until there are no lumps.

Mix together flour, cornstarch,

salt, egg yolks and milk; slowly stir this mixture into the hot syrup. Boil everything until it thickens; then add the vanilla. Pour mixture into a baked pie shell. Make meringue!

Meringue Topping:

- 2 egg whites
- 4 T sugar
- 1/2 t. cream of tartar

Whip the whites in a clean dry bowl on low speed until foamy. Add the cream of tartar and continue whipping on medium speed until soft peaks are formed. Gradually pour in the sugar and continue whipping on higher speed until stiff and glossy. Pile the meringue onto the pie(s) and swirl to cover, making sure to touch the crust on the edges.

Bake pie at 325° until the meringue is slightly browned (approx. 15 minutes). Watch carefully so it doesn't burn! Cool before serving!

About Us

The Interstitial Cystitis Network is a health education and social advocacy company dedicated to interstitial cystitis and other pelvic pain disorders. Our mission is to present the best research, information, and support directly into the homes and offices of our members (patients, providers & IC researchers). In addition to our magazine, newsletters and apps, the ICN offers comprehensive support services for patients throughout the world, including the ICN support forum (www.ic-network.com/forum/), our patient assistance phone line and the “*Living with IC*” educational video series currently available on YouTube (www.youtube.com/icnjill/).

Our contact information:

Interstitial Cystitis Network
PO Box 2159
Healdsburg, CA 95448 USA.
Toll-free: 800.928.7496
FAX: 707.538.9444



The IC Optimist is published four times a year and is available by US Mail (\$50/year) or e-mail (\$25/year). Professional subscriptions are also available.

Material contained in the IC Optimist is copyrighted, all rights reserved. It may not be reproduced in whole, or part, without advance written permission. Reprint requests should be directed to: newsletters@ic-network.com



What is IC?

Interstitial cystitis (IC), also known as bladder pain syndrome, painful bladder syndrome, hypersensitive bladder syndrome or urologic chronic pelvic pain syndrome, is a condition that results in recurring discomfort or pain in the bladder and the surrounding pelvic region. The symptoms can vary greatly between individuals and even for the same person throughout the month, including an urgent need to urinate (urgency), a frequent need to urinate (frequency) and, for some, pressure and/or pelvic pain. People with severe cases of IC/BPS may urinate as many as 60 times a day, including frequent nighttime urination (nocturia).

Pain levels can range from mild tenderness to intense, agonizing pain. Pain typically worsens as the bladder fills and is then relieved after urination. Pain may also radiate to the lower back, upper legs, vulva and penis. Women's symptoms may fluctuate with their menstrual cycle, often flaring during ovulation and/or just before their periods. Men and women may experience discomfort during or after sexual relations.

IC affects patients of all ages, races and cultures. It is found on every continent in the world. Though it was previously thought to be a disease affecting mostly women, new studies suggest that men suffering from chronic non-bacterial prostatitis may also have IC, thus dramatically expanding the population data. It is not unusual for IC to run in families nor for patients to struggle with a syndrome of related conditions including: IBS, anxiety disorder, vulvodynia, pelvic floor dysfunction, allergies, migraines and fibromyalgia.

There are many treatments and self-help strategies now available that can help improve bladder symptoms dramatically. One excellent place to gather information is on the IC Network website (<http://www.ic-network.com>), where you can read extensive articles on IC as well as participate in our support forum and chats.

We welcome you! We believe in you! You are not alone!

"YOU ARE JUST SEEKING PAIN MEDICATION"

Our lives matter. We will no
longer suffer in silence:
Seeking compassionate and
humane pain care.
September is IC awareness
month.

icawarness.org



2017 winning poster - Erin Dryburgh

PosterMyWall.com