

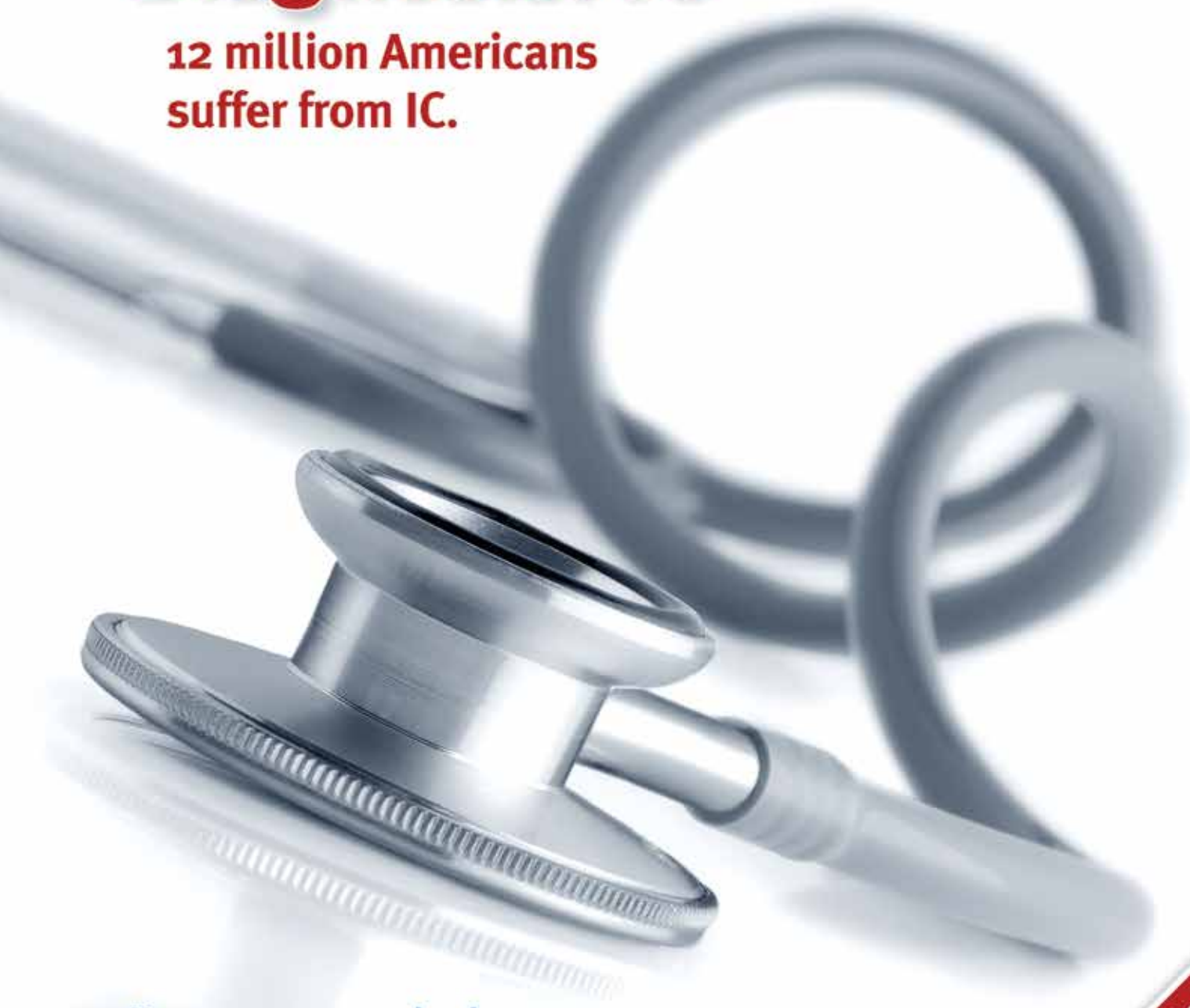
INTERSTITIAL CYSTITIS ASSOCIATION

ICA UPDATE

Summer 2014

Diagnosis: IC

**12 million Americans
suffer from IC.**



**New resources and a deeper
understanding of the condition are helping improve
diagnosis and treatment.**

**Special Clinician
Issue**

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Thanks for your support!



With the generosity of individuals like you, the ICA provides advocacy, research funding, and education to ensure early diagnosis and optimal care with dignity for people affected by IC. Please consider supporting the ICA at any of the following minimum levels. You'll directly help yourself and those who need our help most—other IC sufferers. You'll also receive access to valuable and informative resources that will keep you abreast of the latest IC research, news, and ICA announcements.

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Interstitial Cystitis Association

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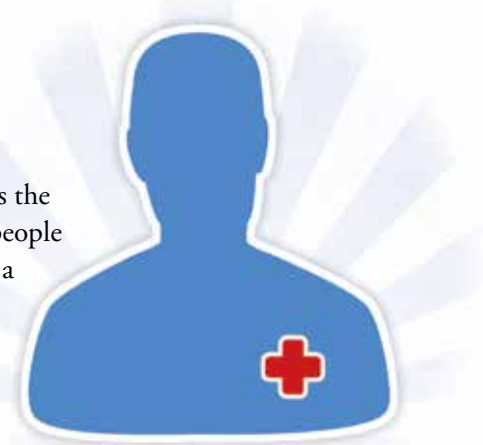
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The Summer 2014 issue of the ICA Update is supported by the Cooperative Agreement number 5U58DP002936-03 from The Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of The Centers for Disease Control and Prevention.

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From ICA's **EXECUTIVE DIRECTOR**



Lee Bryan Claassen, CAE —
ICA Executive Director

No two IC patients are alike, but they all need the same things when they seek medical care. They need to be heard, to be believed, and to be understood.

Regular readers of *ICA Update* may notice that this issue is a little different. Through a grant from the Centers for Disease Control, we're pleased to share this special issue with an important audience—a broad range of clinicians, including primary care practitioners.

As the gatekeepers to medical care, primary care practitioners play a critical role in ensuring that the more than 12 million Americans with interstitial cystitis (IC) are diagnosed quickly and correctly so that they can receive the specialized treatment they need to face this chronic, often debilitating condition.

Sometimes also known as Painful Bladder Syndrome (PBS) or Bladder Pain Syndrome (BPS), IC has no known cause and no known cure. However, a broad range of treatments have emerged from a growing body of research and clinical practice. As with other chronic conditions, treatment of IC is typically multifaceted, encompassing a broad range of providers, from urologists and urogynecologists to physical therapists, dietitians, and pain clinics. Primary care practitioners often sit at the locus of these disparate practitioners. They are also often the ones IC patients call when symptoms flare or trigger other conditions.

In the pages that follow, you'll learn about the most up-to-date thinking about diagnosis and first-line treatment, as well as the role of support in managing IC. We discuss the critical role that diet plays in IC's painful symptoms. Also included are a broad range of resources that practitioners can use and share with their patients, information about a free continuing medical education course focused on IC diagnosis, and the official treatment algorithm. And finally, we share the story of a physician diagnosed with IC, as well as offer advice from IC patients on how practitioners and patients can build an effective relationship while treating the disorder.

No two IC patients are alike, but they all need the same things when they seek medical care. They need to be heard, to be believed, and to be understood. We hope this issue of *ICA Update* will help you better understand both the disease and those who face it every day.

A handwritten signature in blue ink that reads "Lee Bryan Claassen".

Lee Bryan Claassen, CAE
ICA Executive Director

Three Decades of IC Awareness

The ICA works to advocate, support research, and educate on behalf of those with IC.

When the Interstitial Cystitis Association (ICA) was founded in 1984, IC was sometimes still considered a “hysterical women’s disease.” More commonly, though, it was simply unknown—to both patients and the medical community.

Over the past 30 years, ICA has helped build awareness of the disease. IC is now part of the vocabulary of urologists and other healthcare providers. Efforts to research IC and foster awareness are now supported by the National Institutes of Health, the Centers for Disease Control, the Department of Defense, and other funders.



ICA leaders met with key lawmakers to advocate for research and public health initiatives.

empower patients around the country and the world, teaching them to become self-advocates for their healthcare needs.

Research: Each IC diagnosis means a new fight for someone’s spouse, parent, child, or friend. The ICA funds preliminary research, encouraging researchers to gather the data required to obtain larger government grants for further exploration to discover better treatments and ultimately a cure for interstitial cystitis.

As the only nonprofit charitable organization solely dedicated to improving the quality of healthcare and lives of people living with IC, ICA pursues three core functions:

Advocacy: By rallying a grassroots network, the ICA raises awareness among legislators and government leaders about the need for increased levels of dedicated federal funding for IC research. ICA advocacy efforts also help

Education: The ICA’s educational programs bring critical health information and support to IC patients, caregivers,



One of more than 1,000 IC billboards across the country.

and their loved ones. With the increased prevalence of IC, the need for educational programming is expanding. The ICA reach extends to healthcare providers—we work to improve professional educational efforts with the aim of ensuring optimal care with dignity for all people with IC.

In recent years, the ICA has focused on broadening the resources available online to clinicians and IC patients, including an online healthcare provider registry (www.ichelp.org/HealthcareProviderRegistry), an online continuing medical education resource center focusing on



the identification and management of patients with IC (see page 5), and ICHope (www.ichelp.org/ICHope), an online pain management tool for IC patients. A complete list of resources available on ICA’s website is on pages 14-15. For more information about ICA, visit www.ichelp.org.

Your Feedback is Needed Win a tablet computer!

Thank you for taking the time to read this special issue of *ICA Update*. It is our desire to increase awareness and education about interstitial cystitis among healthcare providers. We hope you found the information helpful! We are very interested in your feedback. Please take 10 minutes to complete our survey by scanning the adjacent QR code or going to:



www.surveymonkey.com/s/ICAUpdateSpecialissue

Healthcare providers who complete the survey by August 15, 2014, will be entered into a drawing for a new Microsoft Surface RT 64GB.

Jumpstarting IC Research

The ICA Pilot Research Program helps get critical IC research off the ground.

Since it began in 1985, the ICA Pilot Research Program has funded more than 100 IC research projects, with the goal of identifying the causes of IC and exploring broadly applicable treatments. Funded by the Imagine No IC research fund, the ICA Pilot Research Program is the only IC-dedicated research program funded by a non-profit, patient advocacy organization.

Funded largely by individual contributions, the Pilot Research Program provides awards of up to \$25,000 for novel and useful basic, clinical, or translational research studies that attempt to solve the many questions of IC. A recent matching grant program raised more than \$156,000 for research, with contributions from more than 440 donors matched by a generous anonymous benefactor.

Specific areas of interest include, but are not limited to:

- Epidemiology/burden of disease (especially in children)
- Etiology of IC
- Serum or urine markers
- Treatment modalities
- Neurophysiology
- Pain management
- Pregnancy and IC
- Diet and nutrition

The deadline to apply for the next round of pilot research grants is February 27, 2015. For more information, visit www.ichelp.org/ICAPilotResearchApplication.

2014 Pilot Research Grant Recipients

ICA congratulates three researchers who were awarded ICA Pilot Research Grants in June 2014. These talented investigators seek to improve our understanding of interstitial cystitis with the greater hope of creating a world where IC is a thing of the past.

Larissa Bresler, MD, and her team at Loyola University in Chicago will attempt to determine the safety and tolerability of acupuncture in women with IC/PBS,



Larissa Bresler, MD

as well as determine if acupuncture is effective in reducing pain in women with IC/PBS as compared to sham treatment in a study entitled *Acupuncture for Female Interstitial Cystitis/Painful Bladder Syndrome*. The impact and potential benefits of identifying new nonpharmacologic treatment in women with IC/PBS will be critical to reduce disease severity and improve quality of life across female IC/PBS and all chronic pelvic pain subtypes.

Jayoung Kim, PhD, and her team at Cedars-Sinai Medical Center in Los Angeles will be trying to identify and validate IC-associated urinary diagnostic biomarkers. This study, entitled *Interstitial Cystitis-Associated Microbiome and Proteome As Diagnostic Markers*, has the potential for significant clinical impact because results may lead to clinical methods to increase diagnostic accuracy and an improved understanding of the molecular basis of IC and its relationship to urologic conditions with overlapping symptoms.



Jayoung Kim, PhD



Stephen Walker, PhD

Stephen Walker, PhD, and his team of investigators at Wake Forest University Health Sciences in Winston Salem, North Carolina will be determining whether bladder capacity is a key delineating factor that differentiates IC subtypes in his study, *Correlation of Gene Expression with Bladder Capacity in Interstitial Cystitis*. 

Conquering IC:

Identification and Management Strategies

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- *AMA PRA Category 1 Credits™*
- Continuing Education Credits for Nurses (ANCC)

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Conquering IC: Identification and Management Strategies is an educational curriculum that provides an interdisciplinary audience with comprehensive continuing education on identification and management of patients with IC.

Interstitial cystitis (IC) is a bladder condition that usually consists of multiple symptoms, including but not limited to recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region, and urinary frequency and urgency. IC may also be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain. Early diagnosis and prompt initiation of treatment may translate into better symptom control and improved outcomes for patients with IC.

EDUCATIONAL ACTIVITIES

Peer-to-Peer Podcast Series

Insightful audio commentary from IC experts

Monograph

The latest clinical information on identification and management of patients with IC

Clinician Resources

Links and handouts that provide clinicians and health care professionals with valuable tools for diagnosis, treatment, and management of patients with IC

Patient Resources

Useful tools and valuable information for patients with IC

FOR MORE INFORMATION

Contact ICA at ICAmail@IChelp.org or The France Foundation at 866-856-1998

Visit www.ichelpcme.org

Understanding IC

Difficult to diagnose, IC affects the lives of more than **12 million** people in the U.S. New resources and a deeper understanding of the condition are helping improve treatment.

— By Cheri Smith

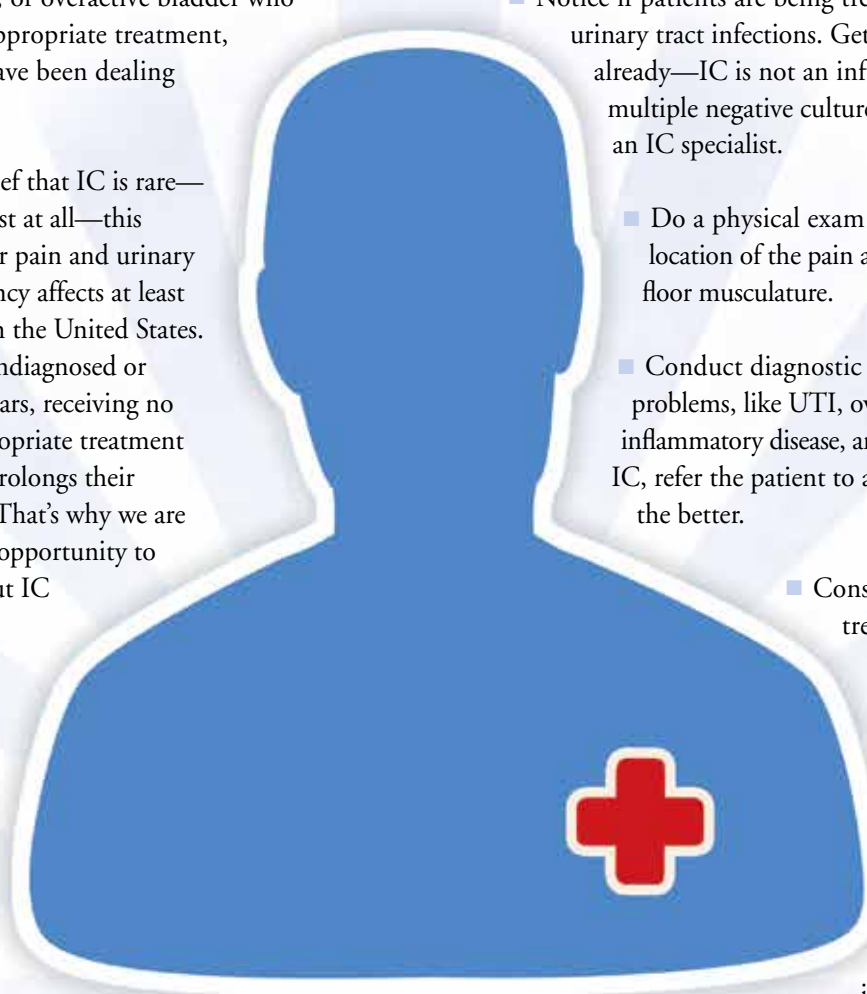
Are you one of the many healthcare providers who have yet to see someone with interstitial cystitis? Think again, because if you've ever had a patient with recurrent urinary tract infections, chronic pelvic pain, or overactive bladder who didn't respond to appropriate treatment, you may actually have been dealing with IC.

Contrary to the belief that IC is rare—or that it doesn't exist at all—this syndrome of bladder pain and urinary frequency and urgency affects at least 12 million people in the United States. Many patients go undiagnosed or misdiagnosed for years, receiving no treatment or inappropriate treatment that unnecessarily prolongs their pain and suffering. That's why we are thrilled to have the opportunity to raise awareness about IC among primary care providers like you, who are often the first to encounter someone with IC and are in the position to guide them to treatment as quickly as possible.

We spoke with several IC specialists to get their recommendations for what primary care practitioners should know about IC. Here are the topics they highlighted, which we'll explore further throughout this article:

- Be aware of IC as a possible diagnosis—when women or men present with pelvic or bladder pain and urinary frequency and urgency, IC should come to mind.
- Notice if patients are being treated repeatedly for urinary tract infections. Get a culture if you haven't already—IC is not an infection. If you see multiple negative cultures, consider referring to an IC specialist.
- Do a physical exam to help pinpoint the location of the pain and to check on pelvic floor musculature.
- Conduct diagnostic tests to rule out other problems, like UTI, overactive bladder, pelvic inflammatory disease, and cancer. If you suspect IC, refer the patient to a specialist—the earlier, the better.
- Consider starting IC treatment with first line, conservative treatments as described in the American Urological Association (AUA) guidelines.
- Help patients find support groups and IC resources, including those at www.ichelp.org (see page 14 for more details).

Detailed IC recommendations are available from the AUA Guidelines on the Diagnosis and Treatment of IC/BPS, which is referenced throughout this article and illustrated in



detail on pages 12-13. Additional information is available at www.auanet.org/education.

The Basics

Also called bladder pain syndrome (BPS), IC is defined by the Society for Urodynamics and Female Urology, and accepted by the American Urological Association, as:



An unpleasant sensation (pain, pressure, discomfort) perceived to be related to the urinary bladder, associated with lower urinary tract symptoms of more than six weeks duration, in the absence of infection or other identifiable causes.

Unfortunately, the symptoms are often mistaken for urinary tract infection or prostatitis, which leads to unnecessary courses of antibiotics that can delay diagnosis. Robert Moldwin, MD, FACS, director of the Pelvic Pain Center at The Arthur Smith Institute for Urology of the North Shore-LIJ Health System in New York, describes a typical scenario: “It’s Friday afternoon, and a woman calls complaining of bladder pain and urgency. It sounds like a UTI and she wants relief now, so you prescribe a course of antibiotics. She’s still having symptoms three weeks later—perhaps not as severe, but still quite bothersome. This time, you send off a urine culture, which comes back negative. Should you empirically prescribe another round of antibiotics? Well...some clinicians do, only to find repeated therapeutic failures.”

This is a common experience among patients who were later diagnosed with IC. You can help patients find effective treatment faster by recognizing certain IC characteristics, such as the type of pain, urgency, and frequency, the presence of co-morbidities, and negative urine cultures.

IC pain can range from mild and annoying to excruciating and debilitating. It’s been described as the feeling of being stabbed with razor blades, or as one patient recently said, “it’s like having your bladder taken out, scrubbed raw with sandpaper, and put back in again.”

Besides the bladder, IC patients might have pain in the lower abdomen, the lower back, urethra, vagina, testes, scrotum, or perineum, or with sexual intercourse or ejaculation. The pain can last from hours to days or weeks; bladder pain may get worse with certain food or drink or as the bladder fills, and it may improve with urination. Some patients feel pressure rather than pain.

Urgency is generally understood as the feeling of needing to use the bathroom right away, with the fear or experience of leaking if you don’t get there soon enough. “With most IC patients, it’s a feeling of persistent urgency—they always feel bladder pressure and, in many instances, don’t feel like the bladder is emptying,” says Dr. Moldwin.

This constant, nagging feeling that they need to go to the bathroom and the desire to get rid of the discomfort is what motivates urinary frequency, another hallmark IC symptom. Some IC patients report going to the bathroom up to as many as 60 times throughout the day and night.

***Be aware of IC as a possible diagnosis—
when women or men present with pelvic or
bladder pain and urinary frequency and urgency,
IC should come to mind.***

“The most important question to ask a patient with frequency and urgency is ‘How would you feel if there is no toilet nearby?’,” says Philip Hanno, MD, Professor of Urology in Surgery at the Hospital of the University of Pennsylvania. “If their answer is ‘I’m going to wet myself,’ it’s more likely overactive bladder. If the answer is ‘I’ll have pain,’ it’s more likely IC.”

Another key factor in the evaluation of bladder complaints is whether the patient has any of the co-morbidities commonly associated with IC. Many IC patients have at least one other condition, including irritable bowel syndrome (IBS), chronic fatigue syndrome, fibromyalgia, endometriosis, vulvodynia, and chronic headaches. There is also a link between IC and depression and anxiety. (This means you should also be on the lookout for IC symptoms in your patients who have those other conditions.)

When discussing the patient’s history, Kristene E. Whitmore, MD, founder and medical director of Drexel University’s Pelvic and Sexual Health Institute in Pennsylvania, urges you to ask about life events that are associated with IC development. “Find out if they’ve had bladder infections, a car accident, a fall on their back, sickness or other body stress, or pelvic surgery,” because these can all be inciting events for IC, she says.

The Interstitial Cystitis Association (ICA) has developed this list of questions to ask patients to help identify IC:

- Do you have pain and/or pressure in your lower abdomen?
- Do you urinate frequently?
- Do you have an urgent need to urinate day and night?
- Do some foods and/or beverages make your symptoms worse? If yes, which foods and/or beverages?
- Do you find that certain types of exercise make your symptoms worse? If yes, which types of exercise?
- Do you have pain during and/or following sexual intercourse?
- If you are a man, do you have discomfort or pain in the penis or scrotum?
- Do tests of your urine fail to show any signs of bacterial infection?

Diagnosis

Due to the complexity of IC and how it presents in individuals, the AUA was unable to find sufficient literature to provide an evidence-based protocol for diagnosis. However, they do provide a framework for determining whether an IC diagnosis is appropriate based on history (as discussed above), as well as physical exam and lab tests to rule in IC and rule out other disorders.

A physical exam can identify or rule out masses, hernia, occult bladder retention, vaginitis, urethritis, and other sources of pain or infection. Including an examination of the pelvic floor muscles to check for tenderness, trigger points, muscle function, and pelvic organ support can help positively identify IC.

A physical exam can identify or rule out masses, hernia, occult bladder retention, vaginitis, urethritis, and other sources of pain or infection.

Pelvic floor dysfunction (PFD) is present in 80 to 85 percent of IC patients. In PFD, the muscles involved in urination, defecation, and intercourse are not functioning properly. Symptoms include pain with intercourse, pelvic or bladder pain or pressure, lower back pain, inner thigh pain, urinary hesitancy, and constipation-dominant IBS.

Identifying PFD is important, says Jennifer Fariello, MSN, CRNP, nurse practitioner for Female and Male Pelvic and Sexual Medicine at Academic Urology in Bryn Mawr, Pennsylvania, because “IC treatments won’t do anything for the patient if the problem is actually stemming from the pelvic floor.”

Urinalysis with culture is recommended to rule out infection, and Dr. Hanno says that it is critical. “You can’t assume that just because urinalysis looks normal that the culture is going to be negative,” he says. “Patients who are voiding frequently and drinking a lot of fluid may dilute their urine enough that bacteria and white cells go unseen.” A culture will determine whether an infection is present; a negative result in patients with bladder symptoms is a red flag for IC.

Tailoring Treatment

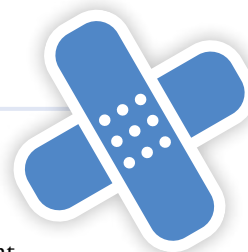
IC treatment is tailored to the specific needs of each patient based on the type and severity of symptoms, and may involve multiple, concurrent treatments. Pain management is also an important component that must be integrated into the plan and reassessed regularly. The AUA Guidelines describe six levels of treatment based on clinical principles. However, the third through sixth lines of treatment should only be done by an IC specialist.

Our expert panel agrees that patients suspected to have IC should be referred to a specialist as soon as possible. But in the meantime, it can help the patient if you start them on first line treatments. These treatments center on patient education, self-care and behavior modification, and stress management.

First Line Treatments

First of all, patients need to understand IC—how the condition affects their body and what they can expect from treatment. You can find printable patient information on the ICA website (www.ichelp.org) that is accurate and informative; a curated list of IC resources is available on page 14 of this issue. If possible, choose a staff member to become knowledgeable about IC so patients have someone in the office to talk to.

Fariello warns against overwhelming patients with too much information at once, though. “Let them know that there’s a lot



to talk about and that you won't be able to go over everything in one appointment," she recommends. It's also good to encourage patients to write down their questions beforehand.

Teaching self-care practices and behavior modification techniques to reduce triggers gives patients a much-needed sense of control over what is happening to them.

People with IC often feel like their bodies and lives are out of their control. Teaching self-care practices and behavior modification techniques to reduce triggers gives patients a much-needed sense of control over what is happening to them. Here are some things patients can do to help themselves:

- Learn about the role of diet. Several foods have been found to trigger IC symptoms, including alcohol, artificial sweeteners, coffee and soda, citrus and cranberry juices, hot peppers, and spices. (More information about diet and IC is covered in the article on page 16.)
- Drink more or less to change the concentration or volume of urine.
- Apply heat or cold to trigger points and areas of pain.
- Learn bladder training to resist urgency.
- Use voiding diaries and food diaries to identify patterns associated with worsening symptoms or relief.
- Identify and avoid exercises that trigger symptoms.
- Wear looser clothing if tight ones cause pain.
- Learn to use meditation or imagery during flares.

Some of these practices are also good for stress relief, which is the final component of first-line treatment.

Some of these practices are also good for stress relief, which is the final component of first-line treatment. Psychological stress is linked to heightened pain sensitivity. You can help patients identify the stressors that lead to symptoms and discuss coping strategies, or refer them to appropriate counseling or other specialists to work on these skills.

Meet the Experts



Jennifer Fariello, MSN, CRNP, is Nurse Practitioner for Female and Male Pelvic and Sexual Medicine at Academic Urology in Bryn Mawr, Pennsylvania.



Philip Hanno, MD, is Professor of Urology in Surgery at the Hospital of the University of Pennsylvania. He is Co-Chair of the ICA Medical Advisory Board.



Robert M. Moldwin, MD, FACS, is the physician in charge of Urologic Infectious/Inflammatory Diseases and Director of the Pelvic Pain Center at The Arthur Smith Institute for Urology of the North Shore-LIJ Health System in New York. Dr. Moldwin is also an Associate Professor of Urology at the Hofstra North Shore-LIJ School of Medicine and a member of the ICA Medical Advisory Board and the ICA Board of Directors.



Kristene E. Whitmore, MD, is founder and medical director of the Pelvic and Sexual Health Institute in Philadelphia, and is a member of the ICA Medical Advisory Board.

Self-motivated patients might benefit from ICHope, a free online behavior management tool designed by ICA to help patients make changes necessary to manage pain and live better with IC. Visit www.ichelp.org/ichope for details.

Second Line Treatments

Second line treatments include physical therapy, pain management, and oral medication. A specialist referral is recommended for this level of treatment, especially for physical therapy.



Physical therapy addresses pelvic floor dysfunction using techniques that:

- Target trigger points in the pelvic, abdominal, and hip regions;

Physical therapy that focuses on strengthening the pelvic floor, such as Kegels, is not recommended because it can make symptoms worse.

- Lengthen shortened muscles; and
- Treat scar and connective tissue problems.

“Many IC symptoms are quelled to a considerable degree by treating pelvic floor problems,” says Dr. Moldwin. “Although PFD is a musculoskeletal, rather than bladder, issue, so many patients have this problem—and are helped by physical therapy—that this approach was included in the guidelines.”

Patients should be referred to physical therapists who specialize in IC, PFD, or pelvic or bladder pain conditions. Physical therapy that focuses on strengthening the pelvic

IC and Men

Long thought to be a female condition, IC also impacts the lives of millions of men.

Like women, men also suffer from IC. And like women, IC symptoms in men mirror those found with other conditions and make diagnosis challenging.

“There’s a general perception that IC is a female condition, and that’s not true,” says Robert Moldwin, MD, FACS, director of the Pelvic Pain Center at The Arthur Smith Institute for Urology of the North Shore-LIJ Health System in New York. “It affects an estimated 2 to 4 million men, and that might be a low number.”

Just as in women, men experience symptoms of pelvic pain and urinary urgency and frequency. However, those are also symptoms of the more common chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS), urinary tract and prostate infection, benign prostatic hyperplasia, and enlarged prostate, so men are often given one of those diagnoses. “We need to be more aware of and sensitive to the fact that men can get IC,” Dr. Moldwin explains.

Misdiagnosis is a problem for men with IC, agrees Jennifer Fariello, MSN, CRNP, nurse practitioner for Female and



Male Pelvic and Sexual Medicine at Academic Urology in Bryn Mawr, Pennsylvania. “We treat a lot of men with IC,” she says. “Men with these symptoms used to be told that they have chronic prostatitis, then given months of antibiotics. When they keep coming in with the same complaints, it’s time to consider IC.”

Besides bladder symptoms, men with IC may also experience testicular, scrotal, penile, and/or perineal pain, as well as painful ejaculation, and—like women—pelvic floor dysfunction.

The AUA Guidelines for IC diagnosis and treatment apply to both men and women.

floor, such as Kegels, is not recommended because it can make symptoms worse.

At this point, there is no magic bullet for the treatment of IC pain, so it's typically treated like other chronic pain conditions using a variety of approaches including medication, physical therapy, counseling, and stress management techniques.

Dr. Whitmore recommends involving a pain manager early on in treatment, and encourages the use of alternative therapies. "You can refer patients to acupuncture, yoga, or meditation," she says. "They're not invasive, and there's enough in the literature now about their benefits." If a pelvic floor physical therapist is not available, Dr. Whitmore suggests looking for a chiropractor or reiki therapist.

At this point, there is no magic bullet for the treatment of IC pain, so it's typically treated like other chronic pain conditions using a variety of approaches including medication, physical therapy, counseling, and stress management techniques.

Second line treatments also include the oral medications amitriptyline, cimetidine, hydroxyzine, pentosan polysulfate, and intravesical DMSO, heparin, or lidocaine. A detailed discussion of each drug is included in the AUA Guidelines.

The more advanced, third, fourth, fifth, and sixth line treatments are to be conducted by a specialist. The ICA's online Healthcare Provider Registry, available at www.ichelp.org/HealthcareProviderRegistry, includes clinicians who have agreed to be a referral source for IC patients.

When it comes to treatment, however, helping patients involves addressing more than their physical symptoms. IC takes a huge toll on the emotions, and you play a key role in that arena as well.

Support

IC has a profound effect on quality of life, equal to that of rheumatoid arthritis and end-stage renal disease. Not only does it hurt, it interferes with work, sexual function, recreational



While there is still no cure for IC, primary practitioners can help make a complicated journey much easier for those who must travel it.

activities, hobbies, travel, and social activities—basically every aspect of a normal life.

You can help by being a sympathetic ear and by guiding patients to appropriate counseling or other support. Dr. Whitmore suggests keeping a few things in mind: counseling may be appropriate if the patient has experienced physical, sexual, or emotional abuse (and Dr. Whitmore says you need to ask about that with anyone suffering chronic pelvic pain), is having relationship issues due to lack of family support or sexual problems, or can benefit from learning coping and stress management techniques (helpful for anyone, but particularly those who catastrophize their symptoms).

Sometimes patients just need to be with or talk to someone who knows what they're going through. Support groups can fill that need, as well as provide the opportunity to learn about treatments and tools that have worked for others. The ICA website has lists of U.S. and international support groups, available at www.ichelp.org/groups. ICA also operates its own online support community, a secure, peer-to-peer moderated forum for patients, family members and friends, and healthcare practitioners. Learn more at www.ichelp.org/OnlineSupportCommunity.

A Primary Role in Fighting IC

Primary care providers play multiple roles for IC patients. They can help speed diagnosis. They can guide patients to IC specialists for more advanced treatments. They can reinforce the importance of self-care and behavior modification techniques to help patients mitigate the effects of IC and respond to triggers that can cause painful flares. And they can provide a sympathetic ear and emphasize the importance of building support structures among friends, family, and support groups. While there is still no cure for IC, primary practitioners can help make a complicated journey much easier for those who must travel it. ✂

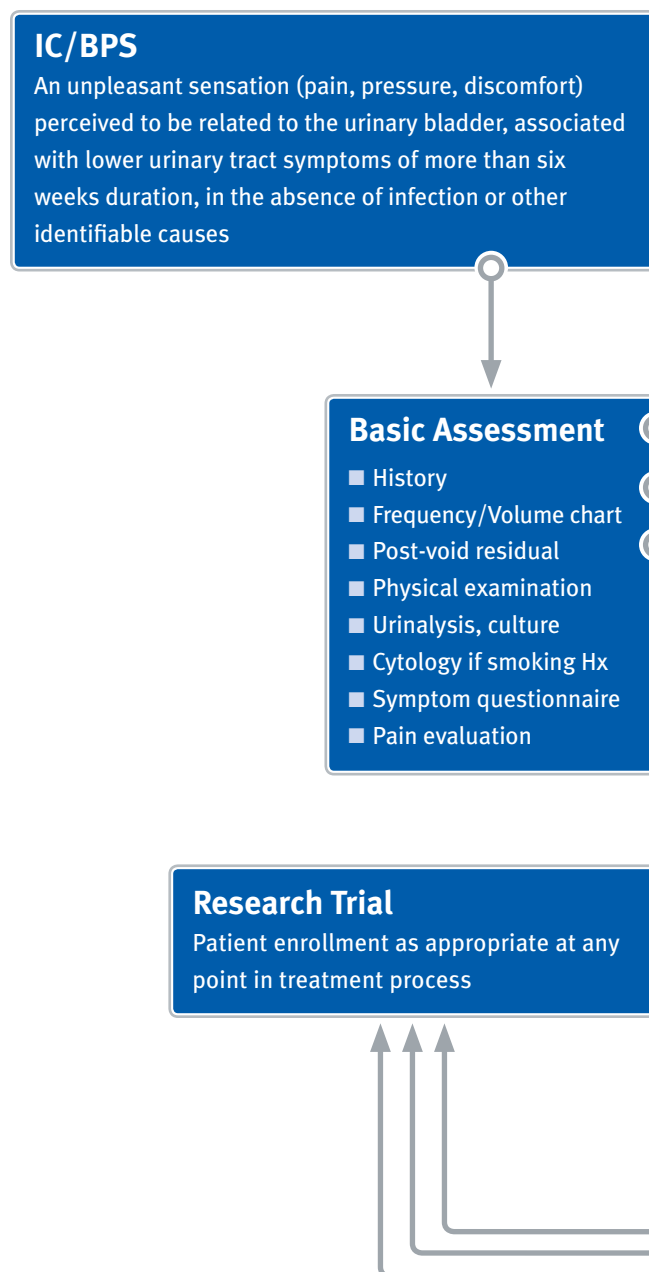
Cheri Smith is a Maryland freelance health writer and coach and a regular contributor to ICA Update.

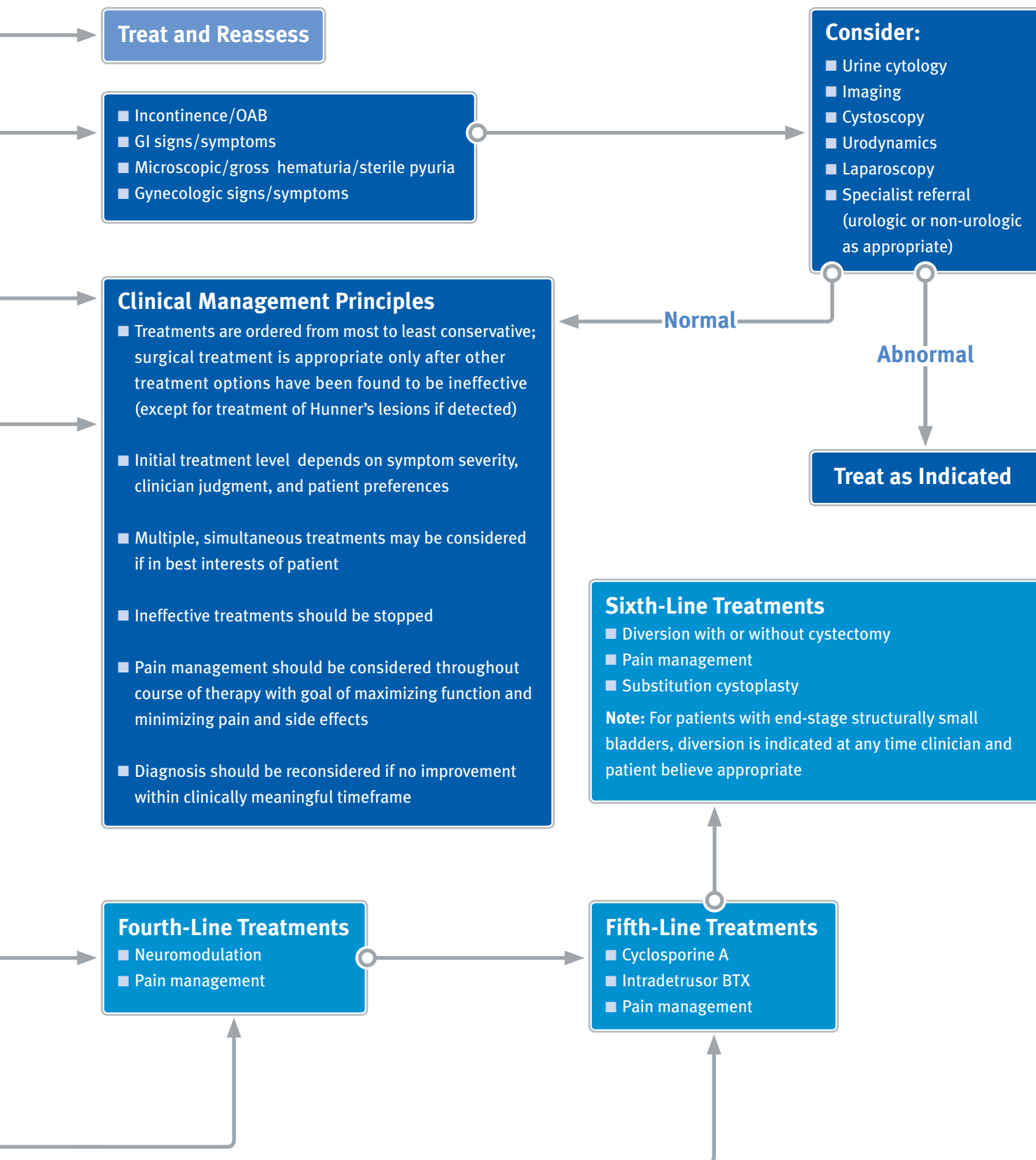


Interstitial Cystitis Treatment Algorithm

American Urological Association

The evidence supporting the use of Neuromodulation, Cyclosporine A, and BTX for IC/BPS is limited by many factors including study quality, small sample sizes, and lack of durable follow up. None of these therapies have been approved by the U.S. Food and Drug Administration for this indication. The panel believes that none of these interventions can be recommended for generalized use for this disorder, but rather should be limited to practitioners with experience managing this syndrome and willingness to provide long-term care of these patients post-intervention.





IC Resources, At Your Fingertips

ICA's website provides a broad range of information and tools for clinicians and their patients.

The following resources are available at www.ichelp.org. Please visit the site and share its information with your patients.

For Patients Newly Diagnosed with IC

- About Interstitial Cystitis Brochure
- Get the Facts on IC Toolkit
- So You Have IC, Now What?: ICA's Newly Diagnosed Patient Toolkit
- The Two-Page Plain Language Summary of the AUA Guidelines for IC
- Frequently Asked Questions
- Glossary of Terminology
- IC Reading List
- IC's Role in CAPPs Webinar
- 2013 ICA Patient Forum Webinars



For Patients Who Need Self-Help Strategies

- ICHope Online Pain Management Tool (www.ichelp.org/ICHope)
- Self-Help Brochure
- Webinar: ICHope Self Management Module – A Staged Approach to Managing IC Pain

For Patients Who Need Support

- ICA Online Support Community
- ICA Facebook Community (www.facebook.com/InterstitialCystitisAssociation)
- IC Support Group List
- ICA Voices of Hope Blog
- ICA Support Group Leader Toolkit
- ICA Ask a Question Email Service (icemail@ichelp.org)

For Patients with Questions About IC Diagnostic Tests

- The Two-Page Plain Language Summary of the AUA Guidelines for IC
- Cystoscopy with Hydrodistention Factsheet
- Potassium Sensitivity Test Factsheet

For Patients Who Need Help Managing Pain

- ICHope Online Pain Management Tool (www.ichelp.org/ICHope)
- Pain Management Factsheet
- Webinar: Safe & Effective Pain Management: The Pros and Cons of Opioids, When Standard Treatments Fail



For Patients Who Want to Stay Up-to-Date on the Latest in IC

- ICA eNews
- ICA Update



For Patients Who Need Help Finding/Working with Healthcare Provider(s)

- How to Talk with Your Doctor About IC Factsheet (Spanish version)
- How to Find the Right Doctor Factsheet (Spanish version)
- The IC Healthcare Team Factsheet
- A Guide to the Healthcare System Podcast
- ICA Healthcare Provider Registry
- ICHope Self Management Module

For Patients Who Need Help with Diet

- IC and Diet Factsheet
- Eating with IC Brochure
- IC Food List
- 2013 ICA Patient Forum Webinar – IC Friendly Fats

For Patients Who Need Help with Intimacy

- Sex and IC Brochure
- IC and Vulvodynia Brochure
- Being Intimate When You Have IC Factsheet
- Helpful Sexual Intimacy Products Factsheet
- 2013 ICA Patient Forum Webinar – A Time for Two: Intimacy, Sexuality and IC

For Patients Interested in Filing for Disability

- Social Security Disability Insurance Factsheet
- ICA Advocacy Efforts Yield Disability Ruling Factsheet
- IC Disability Resources Factsheet
- ICA Introductory Disability Kit
- ICA Personalized Disability Packet
- A Primer on Disability Insurance for People with IC Podcast

For Special Populations with IC

- Children Factsheet
- Pregnancy Factsheet
- IC & Men Brochure
- Webinar: When Standard Treatments Fail



For Patients with IC and Associated Conditions

- Constipation Factsheet
- Pelvic Floor Dysfunction Factsheet
- Webinars: Stretch and Strengthen for a Healthier Pelvic Floor and When Standard Treatments Fail

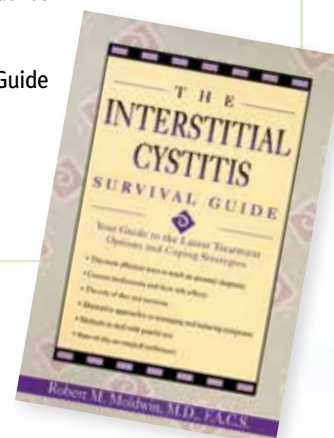
For Patients Who Have Questions About IC Treatments

- The Two-Page Plain Language Summary of the AUA Guidelines for IC
- How to Learn About Your Medicines Factsheet
- Physical Therapy: May Ease IC Symptoms Brochure
- Antidepressants Factsheet
- Antihistamines Factsheet
- Pentosan Polysulfate Sodium Factsheet
- Bladder Retraining Factsheet
- DMSO Instillation Factsheet
- Heparin Instillation Factsheet
- Questions to Ask Your Doctor Before Surgery Factsheet
- Neuromodulation Factsheet
- How to Learn About Your Medicines Factsheet
- 2013 ICA Patient Forum Webinars – When Standard Treatments Fail, Stretch and Strengthen for a Healthier Pelvic Floor, Integral Approaches to Treating IC



ICA Store

- Restroom Access Card
\$10.00 (RAC)
- Brochure Bulk Orders
\$25.00 (25 per pack)
 - About Interstitial Cystitis (PRBG)
 - Living with IC (PRBH)
 - Real Men Get IC (PRBM)
 - Physical Therapy (PRBPT)
 - Sex and IC (PRBX)
 - IC and Vulvodynia (PRBV)
- Eating with IC (PRBD)
\$50.00 (25 per pack)
- Disability Information
 - ICA Introductory Disability Packet
\$18.00 (DISINTRO)
 - ICA Personalized Disability Packet
\$40.00 (DISPER)
- The Interstitial Cystitis Survival Guide
\$10.00 (BKSG00)
- A Taste of the Good Life
\$18.00 (BKTAS98)



The IC-Diet Connection

Research now supports longstanding anecdotal evidence of the role some foods play in exacerbating IC symptoms.

— By Emma Nichols, PhD, ELS

Diet is inextricably related to good health. It can also cause and exacerbate disease, and interstitial cystitis (IC) is no exception. In 2011, the American Urological Association (AUA) published guidelines for the diagnosis and treatment of IC that suggested diet modification as a first line treatment option. The guideline states that patients should “avoid certain foods known to be common bladder irritants for IC... such as coffee or citrus products, and use an elimination diet to determine which foods or fluids may contribute to symptoms.”

The inclusion of diet in the AUA guidelines heralded a novel approach to addressing patients with IC. Until recently, doctors resisted suggesting dietary modifications because there were no empirical findings supporting them. Anecdotal evidence about foods that worsen IC symptoms had circulated among the IC community for years, but research supporting the link was lacking.

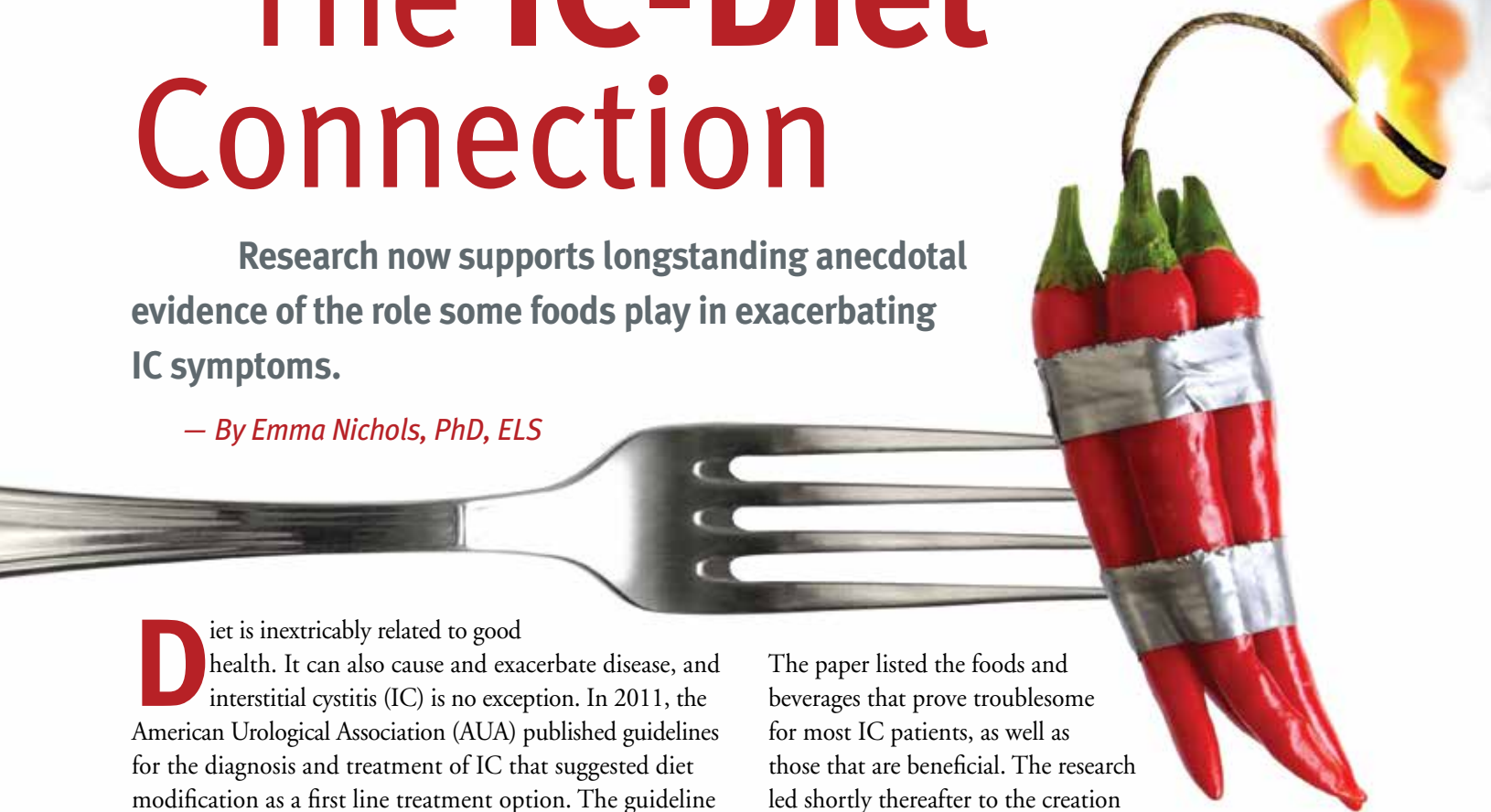
Barbara Shorter, EdD, RD, CDN, associate professor of nutrition at Long Island University and faculty member of the Smith Institute for Urology in New York, investigated the complex interplay between food and IC. In 2007, she co-authored the *Journal of Urology* paper, “Effect of Comestibles on Symptoms of Interstitial Cystitis,” the first of its kind to survey the link between diet and IC. The study used a validated questionnaire to determine the prevalence of food sensitivities in 104 patients with IC to determine the effects of 175 comestible items (in other words, foods) on IC bladder symptoms.

The paper listed the foods and beverages that prove troublesome for most IC patients, as well as those that are beneficial. The research led shortly thereafter to the creation of the “IC Food List” by a team of IC diet experts, including Dr. Shorter. The list, available for free download at www.ichelp.org/ICFoodList, suggests foods and beverages that positively or negatively affect IC symptoms for some or many patients. Foods fall into one of three columns: items in the “bladder friendly” column typically do not cause problems, the “try it” items might cause discomfort, and “caution” items are associated with bladder flares (see page 19 for selected examples).

Dietary Suggestions

“There’s no question that food has a dramatic impact on IC. We’ve found that the vast majority of patients—about 90 percent—report food sensitivity,” says Dr. Shorter, who also has IC. However, she advises patients to keep in mind that the IC Food List is only a guide. “It’s not the final word on what an individual can or cannot eat. Everybody is different. For example, one person might eat tomatoes with no problems, while another person might eat one tomato and be in tremendous pain. It’s highly individual.”

The IC Food List is a comprehensive collection of well over 200 items that may affect some or many IC patients. In an effort



to help healthcare providers streamline the process of discovering food triggers, Dr. Shorter and colleagues, including Robert Moldwin, MD, at the Smith Institute for Urology, devised the “Shorter-Moldwin Food Sensitivity Questionnaire”. This abbreviated tool includes the 35 top offenders that many IC patients find troublesome. The original questionnaire provided a more extensive list of comestibles, but concerns about patients’ loss of concentration and interest prompted the authors to condense it. The statistically validated abbreviated questionnaire, at just three pages, includes demographic information, food sensitivity incidence, and bladder symptoms (frequency, urgency and/or pain), as well as the 35 most offensive and 12 least offensive foods and beverages as determined by the 2007 study.

“This is a tool that we hope will make implementing the AUA dietary guideline easier because it’s brief and simple to administer,” Dr. Shorter explains. “Yet it’s useful for both clinical practice and research purposes. It raises awareness of the possible relationship between foods and symptoms without suggesting that patients limit their foods too extensively. It will also provide a solid data base for future research.”

Julie Beyer, MA, RDN, also contributed to the IC Food List and has written several books on diet and IC. Her first book, *Confident Choices: Customizing the Interstitial Cystitis Diet*, provides information to help people devise a personalized IC diet. The book details the disease, stress management, and exercises that help alleviate symptoms. Over the course of many years counseling patients as an IC diet expert as well as a fellow patient, she has found the food lists to be valuable tools.

She described her approach: “I try to keep it as simple as possible in the beginning. I start with a top 10 list that

Top 10 Foods:

The most common foods causing sensitivity among IC patients:

- Coffee
- Most tea
- Most soda
- Most alcoholic beverages
- Citrus fruits and juices
- Cranberry juice
- Tomato products
- Soy
- Artificial sweeteners
- Hot peppers and spicy foods

Source: Julie Beyer, MA, RDN



primarily came out of the Shorter-Moldwin research.” The top 10 includes coffee, most tea, most soda, most alcoholic beverages, citrus fruits and juices, cranberry juice, tomato products, soy, artificial sweeteners, hot peppers and spicy foods. “Many people can get a significant amount of relief within two to three weeks just by eliminating these. It gives someone who is

newly diagnosed, and already overwhelmed with new ideas, a place to start.”

Many patients have sensitivities to foods beyond the top 10, so when someone is ready to get more detailed, the three-column list comes into play. Like Dr. Shorter, Beyer recommends that the extensive IC Food List be used only as a guide. Some people try to eliminate everything on the list, hoping to solve the problem completely, to the exclusion of other treatments. This is not advisable because eliminating too many foods makes it difficult to achieve a balanced diet. Combined with other treatments, such as Elmiron, which acts to repair a damaged bladder lining, an IC-friendly diet can accelerate relief. But diet alone rarely works.

“Eating tomatoes or drinking coffee is like rubbing sand paper on the wound. We need to give the body the best opportunity to heal and allow other treatments to take effect.”

— Julie Beyer, MA, RDN

Beyer uses the analogy of healing a scraped knee. “Eating tomatoes or drinking coffee is like rubbing sand paper on the wound,” she says. “We need to give the body the best opportunity to heal and allow other treatments to take effect.”

Allowing the body to adjust to diet changes takes time. Many patients fail to recognize a problem food or beverage because they have not stopped consuming it for long enough. This is especially common with coffee.

“A perfect example was one patient who insisted that coffee was not an issue for her,” recalls Dr. Shorter. “I suggested that she give it up for three weeks. After two weeks, she felt the same, but by the third week she actually felt better. It took three weeks to mitigate the bladder pain.” The clincher came when this person drank coffee to stay awake on a road trip and her pain came back. “Now she knows,” Dr. Shorter says. “You have to give the elimination diet a lot of time. Once the bladder is inflamed, it can take a long time before patients start to feel better.”

One of the biggest hurdles to implementing the diet is that some of the most problematic foods, such as coffee and tea, are difficult to give up. Coffee substitutes made from grains like chicory, beets, barley, and rye (marketed with the product names Cafix, Roma, Pero, and Postum) are excellent options for some people.

“But there’s no caffeine jolt. That’s the major issue,” says Dr. Shorter. “I tell people they need to find something to wake them up in the morning, maybe a cold shower.”

For Beyer, eliminating soy was a high hurdle because it appears as an ingredient in many foods. She eventually eliminated it and felt better. “One day, I had a cereal bar, and then started to have severe pain,” she says. “I checked the label and found it had soy protein. It was a blind experiment because I didn’t think I was eating soy. That emphasized the importance of removing it from my diet.” She finds that soy is a problem for most IC patients who consult with her.

The Elimination Diet

As the previous examples illustrate, eliminating, then adding a food back, can pinpoint specific problem items. The cornerstone of a personalized IC diet, an elimination diet entails keeping diaries of food intake, voiding, and bladder symptoms to record the effects of foods and beverages on symptoms. For the first week, patients eat their normal diets. Then, for the next several weeks until their symptoms start to improve, they eat a diet based on foods from the “bladder friendly” category of the IC Food List. Finally, they reintroduce, one at a time, foods and beverages that may be causing problems, all the while keeping a diary of food intake and symptoms.

The term “elimination diet” sounds severe and sometimes intimidates people because it implies taking food away. Beyer sees it in a more positive light in that it allows people to eat with confidence knowing that their diet is not causing harm.

“The foods in the ‘try it’ category, some cheeses for example, cause symptoms in some people, but not everyone,” Beyer says. “If it doesn’t cause a reaction, then why eliminate it? We don’t want to take food away from people, especially food that offers nutrition.”

The “caution” and “try it” foods cause the most problems for the most people, but some people will react to a bladder-friendly item, especially in the case of food allergies.

“Once in a while, I recommend allergy testing when I suspect there is something we are missing,” Beyer adds. “Traditional allergy testing has its place in IC treatment and can help fine tune diet.”

Aside from foods people ingest, medications can also trigger symptoms, often without people noticing or suspecting

the connection. For example, the antidepressant amitriptyline relaxes bladder muscles and is often recommended for IC.

“You then might assume that all antidepressants would be helpful, but there are a few that might irritate the bladder, such as Wellbutrin, Paxil, or Zoloft,” says Dr. Shorter. Similarly, some antihistamines, such as Atarax, are helpful, but some contain ingredients, such as pseudoephedrine, that may be irritating.

“People often don’t realize when medications are affecting their symptoms. Symptoms may worsen immediately or it may take a few days to see the effects,” says Dr. Shorter.

The time between ingesting food and symptom onset varies considerably. Some foods take a few hours, and others, such as coffee or alcohol, trigger symptoms within minutes. Some medications can take a few days.

“We don’t understand how that works, but it could be a number of different factors,” Dr. Shorter says.

The Connection Between Diet and IC

There are several theories as to why certain comestibles cause bladder symptoms. One possibility is that the urothelium is compromised, allowing urine solutes to penetrate into the layers of the bladder wall, causing pain and inflammation. Research has shown that certain proteins involved in the urothelial barrier are fewer in number in patients with IC compared with those with overactive bladder or control patients.

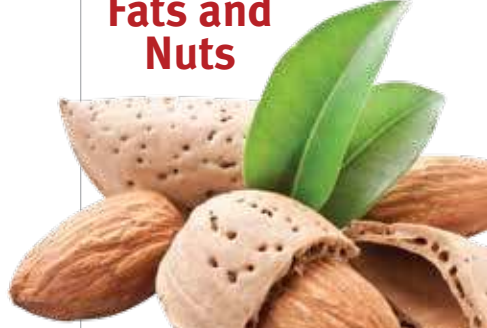
Neurogenic inflammation might also contribute to IC. Research has demonstrated that upregulation of neuronal receptors and signaling factors accompanies cystitis, and that this upregulation is known to play a role in the chronic pain, urgency, and frequency experienced by IC patients. Peripheral nerves stimulate an inflammatory response, which includes mast cell proliferation. Increased mast cell counts are common in IC.

Studies suggest that cross talk between pelvic organs, including the bladder, colon, and uterus, may also underlie IC distress. Pelvic pain may result from the summation of visceral inputs, so that dietary factors affecting the gut may contribute to IC symptoms. Consistent with this theory, irritable bowel syndrome occurs commonly alongside IC.

The IC Diet Food List

Below are examples of several of the categories in the IC Diet Food List. Foods fall into one of three columns: items in the “bladder friendly” column typically do not cause problems, the “try it” items might cause discomfort, and “caution” items are associated with bladder flares. However, experts warn that the list is only a guide, and that different foods elicit different reactions in every patient. The full list can be downloaded for free at www.ichelp.org/ICFoodList, and ICA's *Eating With IC Pocket Guide* is available in bulk for distribution in physicians offices; see page 14 for details.

Note: Foods labeled with a plus sign (+) can be especially soothing during an IC flare.

	Bladder Friendly	Try It	Caution
 Beverages	■ Water: test to find one that works for you ■ Juice: blueberry, pear ■ Milk⁺ ■ Milk Substitutes: almond⁺, rice, Lactaid⁺ ■ Milkshake: vanilla⁺ ■ Tea: chamomile⁺, peppermint⁺ ■ Non-Dairy Creamers: check label ■ Eggnog: nonalcoholic⁺, without problem ingredients	■ Juice: low-acid orange, grape, some apple, baby ■ Coffee: herbal, low-acid decaf, roasted carob ■ Tea: alfalfa, roasted carob ■ Soda: root beer with ice (decaffeinated, not diet) ■ Sports Drinks: test to find one that works for you (e.g., blue Gatorade)	■ Alcohol: not only irritating to the bladder but also contraindicated with many IC medications ■ Water: carbonated, vitamin, flavored ■ Juice: cranberry, orange, acai ■ Milk: chocolate, soy ■ Coffee: regular and decaf ■ Teas: regular, green, herbal, iced ■ Sodas: colas, citrus, orange, diet ■ Drink Powders: such as Kool-aid, lemonade, orange, or powdered ice tea drinks ■ Sports Drinks ■ Energy Drinks: guarana, mate
 Grains	■ Breads: cornbread⁺, oatbread⁺, pita, potato bread⁺, whitebread⁺, Italian sweet bread, whole wheat bread (i.e. Ezekiel) ■ Cereals: most cereals without problem ingredients, oat cereal, rice cereal (hot or cold) ■ Crackers: matzo ■ Grains: couscous, grits, millet, quinoa⁺, spelt ■ Flours: buckwheat, wheat ■ Pasta ■ Rice⁺	■ Breads: rye, sourdough ■ Cereals: instant packaged hot cereal ■ Crackers: without problem ingredients ■ Grain: amaranth	■ Breads: made with unsafe ingredients and/or heavily processed and fortified ■ Cereals: heavily preserved, sweetened, heavily fortified, flavored ■ Flour: soy ■ Pasta: prepared or boxed pasta dishes ■ Rice: Boxed Dishes
 Fats and Nuts	■ Nuts: almonds, cashews, peanuts ■ Butters: almond, peanut ■ Oils: canola, coconut, corn, olive, peanut, safflower, sesame, soy ■ Margarine ■ Lard ■ Shortening ■ Salad Dressing: homemade without problem ingredients	■ Nuts: macadamia, pecans, walnuts ■ Mayonnaise ■ Tahini ■ Seeds: sunflower seeds ■ Shortening: butter-flavored	■ Nuts: filberts, hazelnuts, pecans, pistachios ■ Oils: check label ■ Salad Dressings: most <i>If you have nut or other food allergies, talk with your healthcare provider about your special diet needs.</i>

Acidic Food

Patients and caregivers both struggle to find a common denominator to the foods and beverages that cause reactions for IC patients. Much has been written on blogs, websites, books, and advertisements providing explanations for dietary effects on IC, but many of the theories lack clinical evidence. A common one is that an acid/alkali imbalance causes IC symptoms, an idea that may have arisen from the fact that many of the caution foods on the IC Food List are acidic. People often ask Beyer if they need to avoid acidic foods, believing the acid in the food is causing the problem. She believes this misperception may be part of the reason doctors and dietitians resisted accepting a diet for IC.

“People who have studied biochemistry and physiology know that ‘acid in doesn’t equal acid out’. Acidic foods do not necessarily produce a change in urine pH,” she says. “For example, acidic orange juice forms an alkaline metabolite, and acidic cranberry juice forms an acid metabolite. Discussing the acid/base balance when it comes to foods not only confuses doctors and researchers, but it turns them off. The ideas don’t match what’s known from science and medicine.”

Some studies point to acidic foods (or foods high in citric acid) as exacerbating bladder pain, and alkalizing agents, like sodium bicarbonate and calcium glycerophosphate, as relieving symptoms. However, one study looked directly at the effects of pH in the bladder and found no relationship. The study evaluated urinary pH changes and relief of IC symptoms in 26 women and found no significant difference in pain scores for women receiving instillations at physiological pH (5.0) and neutral buffered pH (7.5).

Many people take calcium glycerophosphate (Prelief) to ward off the ill effects of acid-rich foods, but here, too, it’s not clear that neutralizing acid in the bladder is providing the relief. The Prelief package insert states that, in addition to neutralizing acid, calcium glycerophosphate may have cellular effects.

Inflammation

Since diet plays an important role in inflammation, examining its role in the bladder inflammation characteristic of IC is another topic of interest to researchers. Fatty acids are essential components to any diet, and

the composition of fatty acid intake regulates inflammation. Two types of essential polyunsaturated fats are omega-6 fatty acid, found in liquid vegetable oil and processed foods, and omega-3 fatty acid, found in oily, cold-water fish and, to a lesser extent, in walnuts and flaxseed. The two act in opposition, with omega-6 fatty acid increasing inflammation and omega-3 fatty acid decreasing inflammation. Most Americans consume 20 times more omega-6 fatty acid than omega-3 fatty acid, contributing to inflammation and its complications.

“We don’t know for certain that a diet rich in **omega-3 fatty acid** will **mitigate symptoms**, but IC is an **inflammatory disease**, so it’s worth investigating.”

— Barbara Shorter, EdD, RD, CDN

“There are urine markers that are elevated in inflammatory conditions,” Dr. Shorter explains. “Omega-3 fatty acids have been found to decrease the urine markers that indicate chronic inflammation. We don’t know for certain that a diet rich in omega-3 fatty acid will mitigate symptoms, but IC is an inflammatory disease, so it’s worth investigating.”

Looking Ahead

As research examining diet and IC gains momentum, more clues as to why certain foods affect many (or few) patients may emerge. For now, people should use the tools on hand—the food lists and diet methods—to assemble a healthy, bladder-friendly diet suited to their individual manifestations of IC, Dr. Shorter says.

“When you first learned to drive a car, you had to think about every move you made—turning the blinker on, stepping on the brake pedal, stepping on the gas, turning the wheel. Now everything is automatic,” she says. “That’s what happens with IC. The quicker you learn how to modify your lifestyle, the quicker you return to automatic pilot.”

In the end, an IC diet should be simple. Dr. Shorter emphasizes that it’s not necessary to buy special, expensive foods or exotic health drinks.

“People should be able to go anywhere and select food for a healthy meal wherever they are,” she adds. While developing new habits takes considerable time and effort, the food lists and diet tools available take some of the guesswork out of it. ✂

Emma Nichols, PhD, ELS, is an Atlanta-based medical writer.



Relationship Building

Practitioners and patients share the **responsibility** for creating a solid **working partnership**.

—Joy H. Selak, PhD

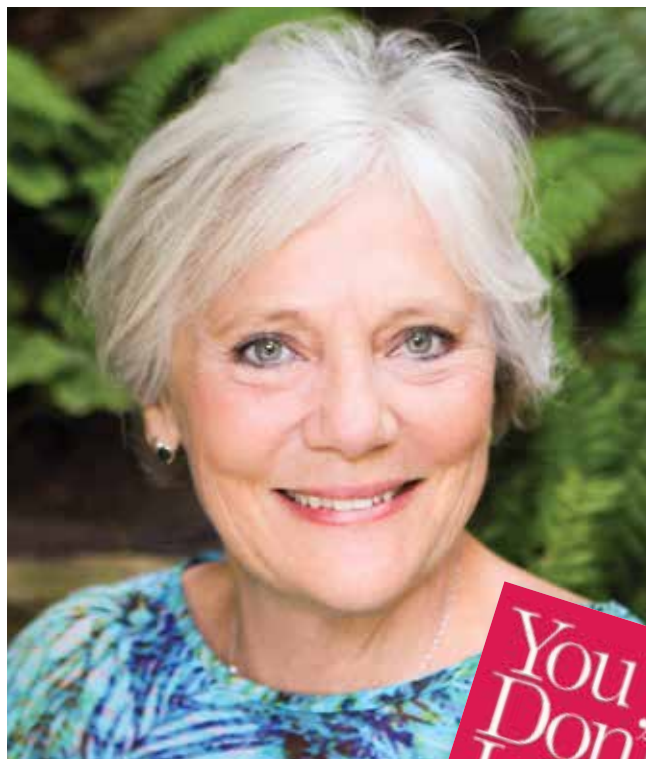
*Joy H. Selak, PhD, is the co-author of **You Don't LOOK Sick! Living Well with Invisible Chronic Illness**, which she wrote with her physician, Steven S. Overman, MD, after becoming too ill to work. Her journey from stockbroker to author came after being diagnosed with IC and other autoimmune and neurological conditions at 40. After two decades of illness, she is now working for an arts education nonprofit and is committed to helping others build meaningful lives with long-term illness.*

Selak joined ICA's board of directors in 2014. She spoke with ICA Update about why doctors have trouble diagnosing IC, how patients should hire and fire doctors, and the things both patients and doctors need to do to ensure a healthy partnership.

Q: What was your own experience with diagnosis and treatment like, and how did that shape your approach to working with physicians?

It started when I first had symptoms and didn't know what was wrong with me, and I went to the doctor a woman of my age would go to—an OB/GYN. I ultimately spent seven years wandering around with doctors saying it was just a virus or not anything definitive.

I was not matching my symptoms to who I was trying to see. Typically what the doctors were trying to do was diagnose me with something within their specialty—the OB/GYN thought I was in early menopause, the general practitioner thought it was viral. It's not so much that I was getting the “it's all in your head” dismissive sort of treatment. I just don't think any of the physicians I was seeing were raising a red flag and saying that this woman wasn't getting better. Or maybe I was too passive.



I finally went to an internal medicine person—an internist's job is to diagnose and refer, and that builds in a specialty pool. I took him by the arm and said, “I know something's wrong, and I'm afraid I'm going to die before I know what's wrong with me. Will you stay with me?” He said, “yes, I will.” I think presenting myself as honestly desperate created a response in him that was positive. He did some tests, and told me he thought I had IC.

He sent me to a urologist. His quiver of options for treatment was one drug—and I had side effects, and he said that most of his patients didn't. And that was that. I looked around his waiting room—it was filled with older men, not younger women like me. So I realized I had to find a urologist that's treating young women who were presenting with my symptoms.

Q: That's a fairly common experience for people with IC. Why do you think this happens?

Dr. Overman, my co-author, and I talked a lot about why doctors can be so delinquent about taking patients' complaints seriously. In talking about it and writing about it, we felt that patients should be more proactive in telling physicians the seriousness of what they're experiencing and moving on more quickly if they aren't successful.

Q: In your book, you talk about hiring and firing doctors.

Explain how this works.

I look at it much as if I'm hiring any professional—an accountant, a stockbroker, a hair care professional. I think for a long time, doctors were exempt from that list—we put them on a pedestal. I was a stockbroker before I was symptomatic, so maybe the idea that my clients were so comfortable with hiring and firing made me look at all the people I paid to provide services to me with a little more authority.

It isn't the doctor's job to be my dream doc—it's my job to find the dream doc. They aren't going to come knocking on my door. I do a lot of speaking with patient groups, and have had the opportunity to talk to thousands of patients with many different illnesses, and I try to share the idea that if you're not happy with your physician, you should go find a different one. I had many women in audiences cry. It was as if they did not have permission to do that. But if you're unhappy with that relationship, only you can change it.

Q: That's a big shift in thinking. What made you realize you needed to make it?

The word "chronic." When you're told this thing isn't going to go away, that it can only be managed, suddenly things change. We've been trained by the American healthcare system to expect you're going to be fixed. But when I began to realize that nobody had that answer, and that there's no known cause and no known cure, then having the very best person to manage symptoms and treatment protocols and lifestyle choices changed the equation for me.

At one point, I made a list of fireable offenses for doctors. It got to the point where it was three strikes and you're out, and I'd move on. That gets tricky with insurance—you have to look like you're not doctor shopping or drug shopping these days—but I think patients are becoming more proactive.

Q: What are those fireable offenses?

I tell people to sit down and make a list of what is essential for them to stay in this relationship and the things they need having to do with their illness. In my case, I have to be believed—the doctor has to signal to me that he or she believes what I am telling them. I have to be treated with respect as a person and a patient—that means being on time, running a business that's well managed.

And both of us have an obligation to be thorough and honest with each other. Everything I expect is also my obligation to give.

Q: How do physicians respond to the idea of being "fired"?

At one point, I was speaking to a group of patients that had peripheral neuropathy. At the end, the neurologist who was the support person for the group came up to me. She said she was glad I talked about patients firing doctors, because it's not so easy for doctors to fire patients. She told me, "I have patients where I know I'm not getting to the problem, or our personalities don't mesh, but I don't have the ability to tell them to find someone else. That really has to be the patient's decision."

Q: What do patients need to do to ensure they get the best care?

It's a two-way street. We need to be better patients. We need to come to meetings with complete information, have our medical records, and have only three questions—not 25. We have to respect doctors' time and get right to the issue. I learned to do that from understanding that they only have 15-20 minutes with each patient.

If you do behave as a well-prepared, informed, and responsible patient, I think doctors respond to that and you get better service.

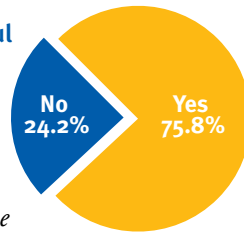
Patients also need to be clear about what a doctor can and cannot do for you. When you're suffering from a chronic illness and scared to death, you need to understand that the doctor is not a therapist. While expecting and demanding that a doctor behave in a professional manner, you have to behave in a professional manner. Patients spend a lot of time in meetings trying to get doctors to be a lot more sympathetic. What they really need is for the doctor to diagnose and treat the disease.

With a chronic condition like IC, I think you have to make peace with it. The thing I hear from doctors about the chronically ill is that the patient won't believe it can't be fixed and isn't willing to accept a treatment or management that works at least for now. You never have to give up hope, but you have to embrace it. That's advice I give from a lot of experience—I live a fulfilling and happy and purpose-filled life that I would not if I continued to resist the reality of living with a long-term illness.

The IC Patient-Physician Relationship

Would you say you have a successful relationship with your healthcare provider?

Source: ICA Survey



ICA asked IC patients about their relationships with physicians, and the majority of the more than 350 people who responded said they have a successful relationship with their healthcare provider. Below are selected responses from the survey:

What one thing makes your relationship with your healthcare provider a success?

- “They believe IC is real.”
- “She uses traditional and nontraditional methods to treat pain and pelvic distress.”
- “My doctor has made it known that if I am having pain, I will be seen that day by her or her nurse.”
- “I can say no to a treatment without offending.”
- “They respect that I do research on my own about my health issues.”
- “She knows that she cannot cure me, but is prepared to do anything it takes to help me cope with the condition.”
- “He understands the toll that IC can take on a patient’s life. He never dismisses any symptoms.”
- “He doesn’t just want to write a prescription and run out the door.”
- “If he can’t answer your question, he will find someone who can.”
- “She is available through e-mail whenever I need her.”
- “I know the nurses say I’m his hardest patient, but he never makes me feel that way.”
- “My relationship with the nurse practitioner, who takes the time to talk.”
- “I have had the same primary care doctor for 15 years, and while he does not totally understand IC, he knows my pain is real.”
- “My urologist is open to trying new things, outside information, and consults with other professionals. She sees it as an opportunity to learn how best to help her patients and applies that information to others.”
- “He is willing to turn over every stone in therapies to provide treatment.”
- “She says, ‘You know your body better than anyone,’ and we go from there on what to do.”

- “We manage my health plan together, taking into consideration my personal and professional life, as well as my personality and temperament.”
- “Three things—competence, caring, and creating an individualized functional approach, meaning addressing the underlying issues and not just prescribing masking medicine.”

What do you wish healthcare providers understood about you as an IC patient?

- “It’s not just about the bladder and not just in our heads.”
- “That diet is a big part.”
- “How this disease has totally changed my life.”
- “That I am not a complainer or stressed out. I am in serious pain most of the time.”
- “The amount of time I am in the bathroom, day and night.”
- “Everything. It’s so upsetting when you as a patient know more, and then you are frowned upon as a know-it-all.”
- “I wish there were better options for pain management.”
- “I wish they were better able to look at you as a whole person and to look at all the conditions as connected.”
- “Realize that sometimes we need compassion and encouragement, and not just another pill to try.”
- “How intertwined my mental/emotional well-being is with my physical well-being. One absolutely will hinder the progress of the other.”
- “That when patients are having a flare of IC, they need prompt attention.”
- “That every IC patient is different and a treatment that works for one person might not work for the next.”
- “That it is a more common ailment than previously thought and all internists should understand it.”
- “That IC seriously affects my sex life.”
- “That I am not willing to try every treatment.”
- “That I do not want to run from doctor to doctor and try to keep dozens of appointments a year. My disease already takes up enough of my life without having to waste more time.”
- “That I mean it when I say that a catheterization really hurts and is a trigger for a week of IC pain.”
- “That IC is very individualized and the chances of a ‘standard’ treatment working are very small.”
- “That after nearly a decade of this, I am broke. Experimenting with one treatment or another is expensive.”

Q: What was it like working with your physician on this book?

Patients like to be told the truth and enlisted as a partner in managing a chronic condition. Dr. Overman did exactly that. He let me know my illness was poorly understood, with no known cause or cure. He said finding the right treatment would be an experiment with many variables. He sent me to alternative practitioners, with whom he had built good communication. My job was to pay attention, keep trying, and report accurately any symptoms or side effects. I tried dozens of drugs and therapies, in many doses and combinations. Each time he let me know my response to treatment was the teacher that would help us find the best answer. I remember him saying that we don't know exactly what is driving your symptoms and pain and how you respond will help us narrow it down and learn how to manage your unique case. I know he is rare, but this is what chronically ill patients need.

Both of us changed as a result of writing the book. I became a different kind of patient, and he became a different physician. He left a big corporate practice and opened his own clinic as a result of wanting to practice medicine differently.

Q: What specific challenges do patients with IC face?

IC is the most widespread disease that no one's ever heard of. It's in the bladder, and it's embarrassing. No one talks about it. Every illness I have has a pain component, but IC has the most devastating kind of pain. There aren't that many diseases that affect daily life as much. But we don't get sympathy because we don't talk about it.

I think it's important for people with IC to get a book, get an article, and get it into the hands of your friends and loved ones and your social circle to let them know about it. We need to take that to all of our doctors and raise awareness. That's the only way more research dollars will become available.

Q: What should doctors do to help improve their working relationships with patients?

I think doctors could do a lot to help patients be better prepared, better informed, and more proactive patients, as well as report more accurately and report the right things. Doctors should let patients know what information they need from them to have that relationship be most efficient. They should give the patient options of things they can do between meetings—increasing or lowering doses based on how they are

responding, the information they need to monitor and report on lifestyle, diet, and medication changes. Doctors should be trained to do those kinds of things instead of sitting behind the desk and passing along information.

So much could also be done over the phone if it were allowed—insurance companies often don't pay. If doctors were able to set aside some time for a telephone follow-up instead of making people who are sick and in pain and exhausted to drive to the doctor's office, that could cut down on a lot of pain.

I also think doctors have an obligation to be on time, or close to on time. It's so disrespectful. Other professionals keep to a schedule, and anyone knows when you're kept waiting for 30 or 45 minutes, the message is that you're not valued. If a doctor has to see one or two fewer patients a day, or even if a nurse would announce in the waiting room that a patient had an emergency so the doctor is running x minutes late—just some show of respect for the patient's time.

Q: How does the dynamic change when doctors and patients are dealing with a chronic condition like IC?

I think a lot of doctors don't like managing chronic illnesses. They want to fix us, and there's a perception of chronic patients never being satisfied. A doctor can do a reality check up front and say this diagnosis has no known cause and no known cure, but there are treatments—some of which may or may not work—so we'll have to work together and be patient with each other and give each other the best information that we can. In my experience, it's not common for a doctor to be up front like that, to say the goal is to get you as stable and functional as possible, but that they can't promise they'll get you well.

There's also the role of outside support—where the MD has identified excellence in areas like acupuncture and dietitians—and established relationships so they will report back and say how things are working for the patient. I find that western physicians aren't willing to admit they won't be able to help cure a condition and that other people besides western medicine can be helpful.

I think adult patients would be relieved to hear this and be invited to join the team, instead of hearing “here, take this” or “none of my other patients have reported that.” Tell the truth, and enlist the patient. 

Mark Toner is editor of ICA Update.

Jane Elsten, MD, Virginia

A physician details her long and difficult path to diagnosis.

As an anesthesiologist, I worked with the disease for many years. After 30 years, I had to retire from medical practice because of my IC. I didn't feel I could give patients the proper attention

It took almost a year to diagnose my IC. I had perineal pain, and I went to my gynecologist—women tend not to go to a urologist first with perineal pain. It felt like I had open burning sores, and he said that I probably had herpes. He cultured me five times on different occasions, and all the cultures came back negative and the pain didn't go away.

As a physician, I knew there's a lot of cross-talk between systems. So I went to a urologist on my own. He did a cystoscopy and thought it was bladder cancer, and told me I had to get to the OR right away. He did a biopsy and it came back non-malignant. He had a female partner, and she was the one who finally said, "I think you might have IC."

The first thing I had to

do, she said, was to drink a lot of water and go on a diet where you eliminate most foods and gradually start adding them back in.

In the meantime, I was going to work every day, I still had persistent pain. When you're in the OR, you can't medicate—you can't take anything that's going to impair yourself. The dietary restrictions can feel like a condemnation, and the lack of ability to get any help is really disturbing.

Eventually the pain became so severe that I couldn't sit or walk comfortably. I finally went on disability to find a treatment. I went to a number of specialists over a couple of years. One decided I had a neurological condition.

I went to another specialist who prescribed a steroid compound. I went to a urologist who wanted to implant a device in my lower back. I went to see a neurosurgeon who suggested delicate nerve surgery. Finally, I found my current urogynecologist. He knew IC and did a cystoscopy, during which he recognized the bleeding ulcers in my bladder, and that they were causing the pain. That was my chief complaint years and years before when I first went to the gynecologist, and finally someone understood.

I had surgery for the Hunner's ulcers. I had been very anemic—at one point, I had almost passed out while I

was wheeling a patient into the recovery room. I was bleeding into my urine, and nobody would believe that was the cause of my anemia. Once I had the ulcers treated, the hemoglobin went back to normal within a short period of time. I got really good pain relief for about a year. Then I had to go back and do the surgery again. But the IC is still with me, and I know I will need the surgery again.

It's frustrating that no one's been able to identify the cause of IC, and in my case there was no effective treatment other than invasive surgery. I don't know how people

without medical backgrounds do it. I think the internet has helped because there's a lot more information. The ICA has been enormously helpful in disseminating information and helping people who would otherwise be desperate.

Finding someone who gets IC is critical—and they're few and far between. Before putting someone on medications, physicians should explore other diagnoses and send patients to other specialists. It's like the blind men and the elephant—someone's going to be able to see the whole picture and help them out.

“It's frustrating that no one's been able to identify the cause of IC, and in my case there was no effective treatment other than invasive surgery. Finding someone who gets IC is critical—and they're few and far between.”

— Jane Elsten, M.D.

To read more stories or submit your own, visit www.ichelp.org/VOH.



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What Is Interstitial Cystitis?

Interstitial cystitis (IC), also known as painful bladder syndrome (PBS) and bladder pain syndrome (BPS), affects as many as 12 million Americans—of all ages, genders, races, and ethnicities. For people living with IC, pelvic pain, pressure, or discomfort related to the bladder is typically associated with a persistent urge to void or urinary frequency, in the absence of infection or other pathology. Symptoms of IC can be continuous or can wax and wane. People with IC often describe their pain as a deep ache in their pelvic area. Others with IC describe their pain as like having razor blades cutting their insides apart. Although there is no cure, there are effective treatment options.

What Is the ICA?

The Interstitial Cystitis Association (ICA) is the only nonprofit charitable organization solely dedicated to improving the quality of healthcare and lives of people living with IC. The ICA provides advocacy, research funding, and education to ensure early diagnosis and optimal care with dignity for people affected by IC.

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