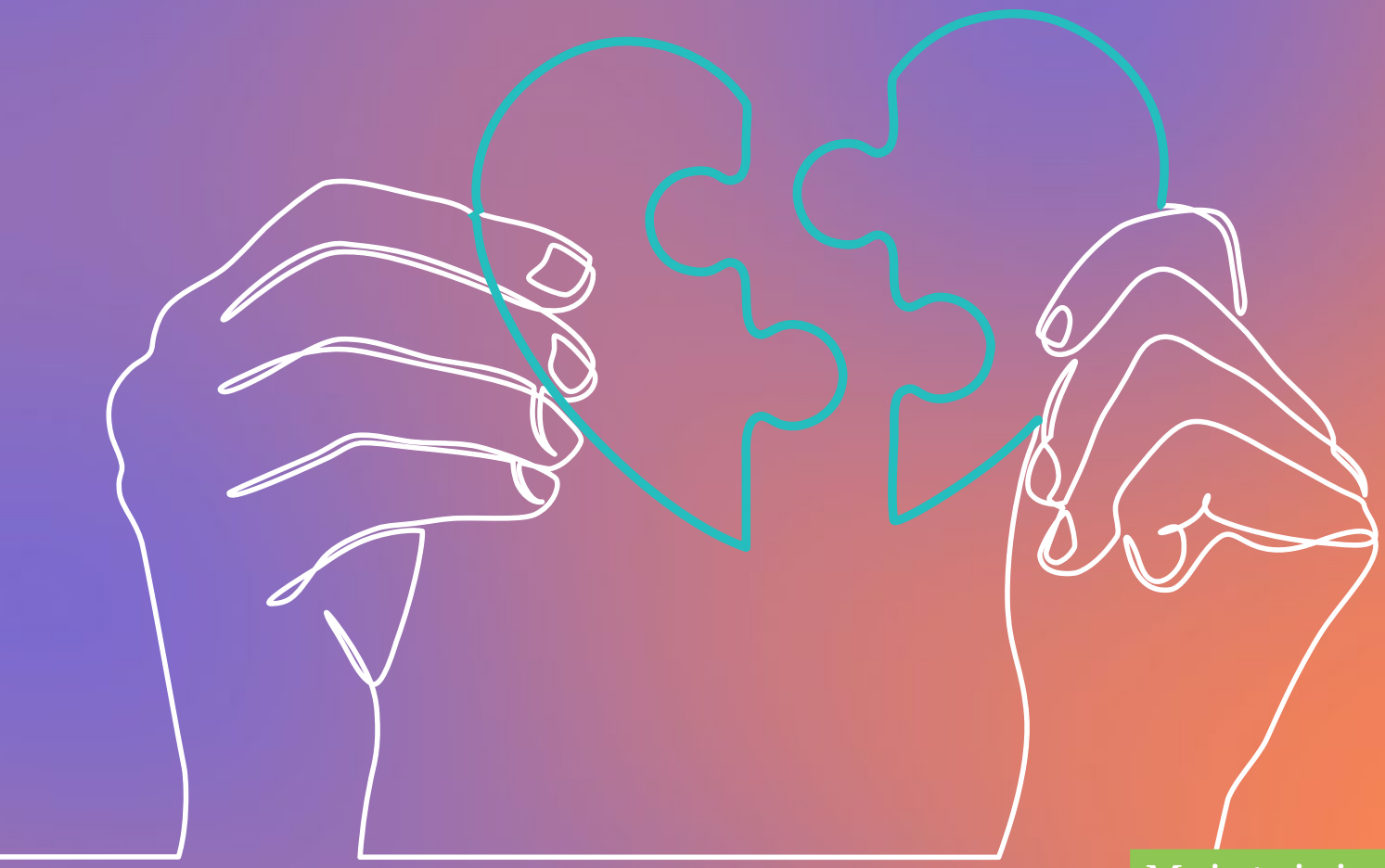
INTERSTITIAL CYSTITIS ASSOCIATION

ICA UPDATE

Spring/Summer 2026



Maintaining– or restoring– intimacy while living with IC/BPS.

IC/BPS and Sexual Health

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We're thankful for the generosity of individuals like you. Thanks to your donations, the ICA provides advocacy, education, and community to ensure early diagnosis and optimal care with dignity for people affected by IC/BPS.

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Your tax-deductible contribution may be made conveniently online at ichelp.org/donate.

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Interstitial Cystitis Association

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IN THIS ISSUE

ICA Holds Advocacy Day; CDC Doubles IC Education and Awareness Program Budget

The ICA Board of Directors and staff were on Capitol Hill on February 11, 2026, to represent the patient voice and advocate for much-needed federal research funding for interstitial cystitis/bladder pain syndrome (IC/BPS). Patients deserve answers, better treatments, and real progress.

We're thrilled to share a major milestone: through sustained advocacy and the powerful voices of IC/BPS patients nationwide, the CDC IC Education & Awareness Program budget has been doubled from $1.1 million to $2.1 million, meaning more clinician awareness, broader public outreach, and a faster path to diagnosis for patients still searching for answers. We're proud of this momentum and committed to keeping it going.

Interested in getting involved in advocacy? Check out www.ichelp.org/get-involved/advocate/ to learn more!

New *IC Talk: A Patient Forum* Webinars Held Quarterly

In January, ICA hosted its first *IC Talk: A Patient Forum*. Moderated by ICA Executive Director Dr. Laura Santurri, the quarterly webinars feature an anonymous panel of individuals living with IC/BPS. The sessions are not intended to provide medical advice, but to be a supportive space to ask questions and learn from fellow patients' experiences. To protect confidentiality, the sessions are not recorded, but ICA has posted anonymous written summaries of the January (bit.ly/ICPF-Jan) and April (bit.ly/ICPF-April) webinars.

The next patient forum will be held in July.

ICA's Monthly Webinar Series

Each month, the ICA hosts a free virtual webinar as part of our Monthly Webinar Series. Among the topics so far this year:

- January: *IC Talk: A Patient Forum* (see above).
- February: Drs. Jennifer Anger, Karyn Eilber, and Victoria Scott presented Interstitial Cystitis: 'The Great Imitator.' The doctors delved into the differ ent conditions that IC mimics and the conditions that mimic IC.
- March: Amber Carter-Frauenhofer, ICA Board Chair, presented Botox & IC/BPS: A Patient's Perspective.
- April: *IC Talk: A Patient Forum* (see above).
- May: Urologist Dr. Joseph DiTrolio, who discussed the science behind Prelief and its role in dietary management of IC/BPS. This webinar was sponsored by DSE Health Solutions, makers of Prelief.

Recordings of past webinars are available on ICA's YouTube channel (www.youtube.com/@ICHelp).

ICA @ AUA Summit

A huge thank you to ICA volunteer Dr. Tony Buffington and board member Ilka Ross for representing the Interstitial Cystitis Association at the American Urological Association (AUA) Patient Advocacy Connections Program (PACP) and AUA Summit in Washington, DC!

Alongside urologists and fellow patient advocates, they took their seats at the table—and their voices to Capitol Hill—to ensure that the needs of IC/BPS patients are

heard by the people who make the decisions that matter most. From advocacy training to face-to-face meetings with lawmakers, Tony and Ilka showed up for our community in the most powerful way. We are so grateful for their dedication and passion.

Together, patients and physicians are stronger. Together, we demand change.

Learn more about the AUA PACP at auasummit.org/pacp.

The Connected Journey: Life with IC Podcast

ICA's The Connected Journey: Life with IC podcast is designed to allow our patient community to share their stories and build connections. We're defeating isolation one story at a time!

Hosted by Laura Santurri, ICA's Executive Director, the podcast allows our patient community to share their stories and hear one another's experiences. Episodes are available on YouTube and Apple Podcasts; for links and more information, visit bit.ly/ICA-podcast.

Guests and topics to date include:

- Maya Van Wagenen on living and writing with IC.
- Jen on stress, resilience, and living with IC.
- Kristin on how discovering Pain Reprocessing Therapy (PRT) transformed her relationship with pain by helping her rewire thought patterns, build trust in her body, and approach healing with mindfulness and self-compassion.
- Nativa on diagnosis and her transformative experience with neuromodulation using an Axonics implant.
- Iris on healing and empowerment in dialectical behavior therapy (DBT), creative expression, and self-care practices like yoga, journaling, and mindful ness (listener discretion is advised).
- Ashley Walcott on her 20-year journey living with interstitial cystitis—misdiagnoses, chronic pain, and the difficult path to finally getting answers at age 28.
- Amber to discuss her nearly 20-year journey living with interstitial cystitis and bladder Botox.
- Vivian, originally from Venezuela, on her decades-long struggle to find answers for her bladder symptoms.

Interested in being on the podcast? Anyone living with IC/BPS who is over 18 is invited to express interest. Guests are not required to have any prior public speaking or podcast experience but should have a reliable Internet connection. Visit ichelp.org/stories to learn more and complete our interest form!

Sign Up for ICA's Research Digest

ICA's monthly Research Digest translates timely and relevant scientific literature to equip our community with the knowledge needed to make the best possible decisions regarding their care.

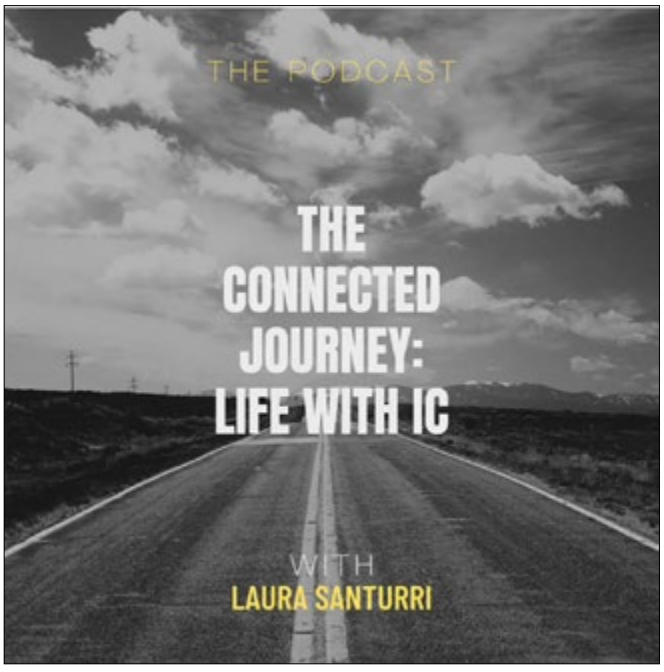
Each issue includes summaries of recent studies that apply to those living with IC/BPS, which includes research on common co-morbid conditions (i.e., other conditions that are common in IC/BPS patients).

See highlights on p. 23 and visit bit.ly/ICA-RD to sign up.

Coming Soon: ICA's New Website

A brand-new ICA website is launching this summer at ichelp.org, featuring expanded, evidence-based information in a cleaner, more intuitive format. Meanwhile, our core programs, including the monthly newsletter, Ask an IC Question, Voices of Hope, the Research Digest, and the Connected Journey: Life with IC podcast, continue serving our community every day.

Your gifts sustain this work, fuel the advocacy changing



policy, and build tools that will serve our community for years to come. A gift of $50 distributes one edition of the Research Digest, $100 supports a podcast episode, $250 hosts an Expert Speaker Series webinar, and $500 provides free Voices of Hope attendance for one person. No matter the amount, your contribution makes an immediate and lasting difference for people too often suffering in silence. To learn more, visit ichelp.org/donate.

ICA's 2025 Annual Report

The ICA's 2025 annual report is now available and provides a review of the organization's major activities and accomplishments during the last calendar year. The ICA follows best practices for nonprofit organizations. The Board of Directors, comprised of volunteer professionals, some of whom are also IC/BPS patients, guides the ICA's organizational priorities. Annual financial audits are conducted by an independent auditing firm. Read the report at bit.ly/ICA-AR2025.

ICA Holds Virtual Movie Night

ICA held its first-ever virtual movie night, followed by a live panel conversation on May 7. Featuring *Lady Parts*, an award-winning dramedy based on a true story that follows a young woman navigating years of vaginal pain, a vulvar surgery, and the very real, very awkward experience of moving back home while figuring it all out, the virtual night concluded with a conversation about bladder symptoms, pelvic pain, intimacy, and what this actually looks like in real life, led by Dr. Jill Krapf, Dr. Alicia Jeffrey-Thomas, Sara Edwards, Bonnie Gross, and Callie Krajcir.

Help Us Grow the ICA Healthcare Provider Registry!

We know how hard it can be to find knowledgeable, compassionate care for interstitial cystitis/bladder pain syndrome (IC/BPS). The ICA is working to expand our Healthcare Provider Registry—and we need your help.

Have you had a positive experience with a healthcare provider who understands IC/BPS or helps you manage life with chronic pelvic/bladder pain? We're looking for recommendations for providers of all specialties, including but not limited to urology, urogynecology, physical therapy, and mental health.

Submit your recommendation using our online form at bit.ly/ICA-PRform. Having issues accessing the form? Email us instead at ICAmail@ichelp.org.

Visit ICA's Online Stores!

The ICA has not one, but two online stores with merchandise and useful tools.

The ICA online store includes restroom access cards, healthcare practice and provider materials, ICA wristbands, and IC Hope bracelets. The ICA Bonfire store offers a variety of items for the ICA community, including clothing items, mugs, and tote bags. A portion of each purchase comes back to the ICA to help support the free resources we provide to the IC/BPS community. To learn more, visit www.ichelp.org/icashop/.

IC/BPS and Sexual Health

Maintaining—or restoring—intimacy while living with IC/BPS.

BY MARK TONER

Dr. Christine Vaccaro, DO, FACOG, MSCP likens the pain associated with intimacy and interstitial cystitis/bladder pain syndrome (IC/BPS) to "putting a hand on a hot stove."

"When patients know they're going to be in greater discomfort, they're not going to want to engage with sex," says Dr. Vaccaro, associate professor of gynecologic surgery and obstetrics at the Uniformed Services University of the Health Sciences and a retired U.S. Army colonel. "It's not normal to have sexual pain, but it is normal to be afraid of sex with sexual pain," she says.

The results can be devastating—to desire, trust, relationships, and our own self-image. But treatment, communication, and help from our partners can all help address the underlying issues and improve sexual health.

"Does bladder pain affect sexual function? Truly," Dr. Vaccaro says. "We also know treatment improves sexual function because of decreased urgency, frequency, pain, and symptoms after sex."

A CONDITION AFFECTING MILLIONS

While not often discussed openly, as many as 40 percent of women report having concerns about sexual function, according to the American Medical Association. And between 10 and 20 percent of women in the U.S. experience persistent pain before, during, or after sex—a condition called dyspareunia, according to The American Sexual Health Association. That adds up—to as many as 20 million people, primarily women, who experience painful intercourse or pelvic pain with intimacy.

The reasons behind dyspareunia can be wide-ranging, from vulvodynia and other vaginal conditions to injury, endometriosis, pelvic inflammatory disease, uterine issues, menopause and hormonal issues, and, of course, conditions involving the bladder, including IC/BPS.

"Any urinary symptoms can affect sexual health," Dr. Vaccaro says.

For IC/BPS patients, symptoms can run the gamut. Along with pain, "women often feel urgency during sex, which is unpleasant," Dr. Vaccaro says. Others may experience leakage during intercourse—or are fearful of leakage, which can "affect psychological comfort," she says.

And psychological comfort—or, more accurately, the lack thereof—can make all of these symptoms worse. Like

putting a hand on a hot stove, pain can lead to a fear of recurring pain, which can increase stress. Increased stress, in turn, can increase the likelihood of additional pain and making intimacy even more difficult, according to the Mayo Clinic.

"Over time, these experiences can create a reinforcing cycle where pain leads to fear, fear leads to avoidance, avoidance increases muscle tension and nervous system sensitivity, and that increased sensitivity leads right back to more pain," writes Dr. Nicole Cozean, PT, DPT, WCS, founder and owner of PelvicSanity and author of the *Interstitial Cystitis Solution* (see p. 10). "Breaking this cycle is one of the most important steps toward improving quality of life, and it is absolutely possible with the right approach."

BREAKING THE CYCLE

Whether caused by IC/BPS or other conditions, the primary approach to treating dyspareunia involves addressing the underlying issues. For patients with IC/BPS, that means focusing on the wide range of treatments and therapies recommended in the American Urological Association's guideline, tailored to each patient's symptoms and needs.

Dr. Vaccaro has seen patients with a wide range of symptoms, from formal BPS diagnoses to others who have never been diagnosed but are voiding 15 times a night, she says. She conducts a urinary sexual health assessment of all of her patients, during which she asks about urgency, frequency, and whether sexual pain occurs during or after intercourse.

"All of this helps me figure out where to target therapies," she says.

In general, she says, patients who experience pain during sex tend to have tight pelvic floors, while those who experience lingering pain after intercourse tend to have more inflammatory symptoms. In either case, she says, "the goals of treatment would be not only reducing day-to-day symptoms, but also the sexual symptoms so their libido isn't affected by their symptoms."

The AUA guideline outlines a wide range of treatments for IC/BPS symptoms, including diet and stress management and a range of medical interventions, including pelvic floor physical therapy (PFPT), medications and instillations, Botox, and sacral nerve stimulation.

Pelvic floor physical therapy is a common strategy for a wide range of dyspareunia-related conditions involving the pelvic floor, including IC/BPS. It also has among the strongest evidence bases for addressing IC/BPS symptoms among existing treatments (see p. 10 for more details).

Dr. Vaccaro says that physical therapy is particularly helpful for patients who have had symptoms for a long time, as long-term pain stimuli tends to stress the pelvic floor. She adds that physical therapists who specialize in the pelvic floor also often "do a great job of educating patients on bladder irritants."

ICA Update readers also gave PFPT high marks in addressing intimacy issues. "The fact that the internal exam also triggers BPS symptoms was confirmatory," one wrote. "Pelvic floor relaxation helps manage the symptoms."

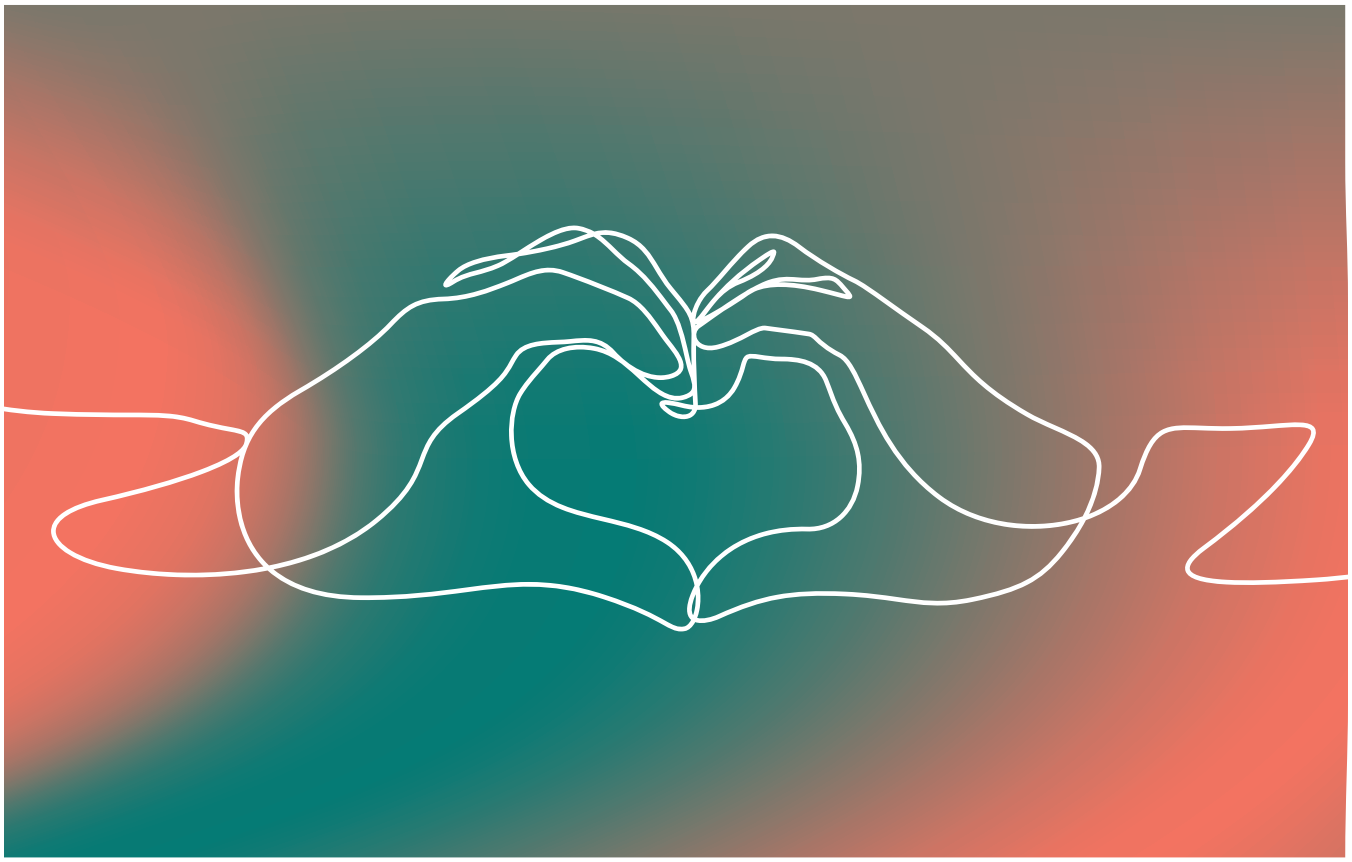
"Being open with a physical therapist who specializes in IC was incredibly helpful, as she was able to give me stretches and exercises I could do prior to intercourse that would relieve my pelvic floor pain," another added.

"Breaking this cycle is one of the most important steps toward improving quality of life, and it is absolutely possible with the right approach."

While the idea of pelvic floor physical therapy may make some patients uncomfortable, readers urged IC/BPS patients to consider trying it. "Of course, I felt hesitant at first to allow someone to work on me in that way," one wrote. "But it turns out her caring and respectful approach has been very helpful both physically and emotionally.

Others noted that good physical therapists often share strategies that go beyond the treatment room. "I'm grateful that this work can lead to my ability to have intercourse again through the use of several tools and approaches she is teaching me to use," one wrote. "One tool allows a male partner to have the experience of intercourse without needing to penetrate very far into his partner. This particular type of PT can have many tricks and ideas up their sleeves, so I highly recommend!"

IC/BPS patients also have developed many strategies that have helped them maintain physical intimacy. Those



responding to *ICA Update's* survey cited a wide range of approaches, ranging from lubricants and medications to specific sexual practices (see box, p. 9).

RESTORING THE MIND-BODY CONNECTION

Physical symptoms are only one piece of the puzzle. Dr. Vaccaro also recommends working with a therapist or sex therapist to help restore the mind-body connection. In this way, she says, patients with longstanding pain can begin to "trust their bodies again," she says.

Couples therapy can also help patients and their partners address misconceptions and hard-to-discuss emotions around intimacy. "I think having a third party that can normalize these conversations can be immensely helpful," says Jill Solomon, MFT, a Los Angeles licensed marriage and family therapist (see interview, p. 15). "Therapists can provide communication tools and create a safe space for important and challenging conversations to happen together. It is an invaluable part of the equation when confronting a chronic illness like IC."

Two keys for patients and partners, *ICA Update* readers say, are reframing intimacy and communication (see p. 25). One writes, "It's taken us a while to learn to communicate well together. I think what's been most helpful for us has been working with an excellent couples therapist."

Another strategy involves reading—and discussing—books about relationships and intimacy together. One *ICA Update* reader recommended *In Each Other's Care* by Stan Tatkin and *Come as You Are* by Emily Nagoski (see resources, p. 9). "It's helped for us to read an agreed-upon section of a book, and then have a chance to sit down and talk together about what we need," they said.

STEPS TOWARDS SEXUAL HEALTH

Articles throughout this issue address these strategies in more detail. Dr. Cozean discusses how pelvic floor physical therapy can guide a gradual and supported progression back to intimacy on p. 10, and Solomon describes the benefits of communication among partners and couples therapy on p. 15. Finally, *ICA Update* readers share five things that help them and their partners reframe intimacy on p. 25.

Together, these strategies can help IC/BPS patients reclaim something many feel they had lost. "Everyone's life story is different, and each couple gets to write a unique story of intimacy together," Solomon says.

Mark Toner is editor of ICA Update.

STRATEGIES FOR INTIMACY

ICA asked IC/BPS patients what helped them maintain physical intimacy. While their responses varied widely, keep in mind there is no one-size-fits-all approach, and what may work for one person could potentially exacerbate issues for others. Patients should discuss their options with a healthcare provider.

- Lubricants/gels
- Dilator therapy, with or without a partner
- Vaginal diazepam tablets
- Methenamine (a prescription urinary antiseptic)
- Essential oils
- Compounded prescriptions an hour before intimacy (e.g., Elmiron, ibuprofen)
- "A jar of good organic coconut oil in the nightstand."
- Estrogen cream "on non-romantic nights."
- Condoms with lubrication
- Vaginal pessary
- Physical therapy and trigger point massage
- Washing genitals with a water-only wet wipe after sex
- Organic drops supporting mood and libido
- Oral sex
- Mutual masturbation
- Foreplay without penetration

FOR MORE INFORMATION

- **"What doctors wish patients knew about pain during sex," American Medical Association,** *www.ama-assn.org/public-health/population-health/what-doctors-wish-patients-knew-about-pain-during-sex*
- **"Painful intercourse (dyspareunia)," Mayo Clinic,** *www.mayoclinic.org/diseases-conditions/painful-intercourse/symptoms-causes/syc-20375967*
- **American Urological Association Guideline for Diagnosis and Treatment of IC/BPS (2022),** *www.auanet.org/guidelines-and-quality/guidelines/diagnosis-and-treatment-interstitial-of-cystitis/bladder-pain-syndrome-(2022)*
- **When Sex Hurts by Andrew Goldstein,** *MD, Caroline Pukall, PhD, and Jill Krapf, MD.*
- **In Each Other's Care by** *Stan Tatkin.*
- **Come as You Are by** *Emily Nagoski.*
- **Lady Parts (2024),** *an award-winning dramedy feature film (see p. 4).*

Reclaiming Intimacy

IC/BPS can impact your sexual health, but there are real, evidence-based ways to reduce pain and rebuild connection. Pelvic floor physical therapy can guide a gradual and supported progression back to intimacy.

BY DR. NICOLE COZEAN, PT, DPT, WCS

If you're living with interstitial cystitis/bladder pain syndrome (IC/BPS), you already know how deeply it can affect your daily life. What's talked about far less—but matters just as much—is how IC/BPS can impact your sexual health, your sense of self, and your relationship with your partner.

Pain with intimacy, fear of flares, decreased desire, or feeling disconnected from your body are incredibly common experiences, and many people feel isolated in this part of their journey. You are not alone in this, and more importantly, there are real, evidence-based ways to improve sexual health, reduce pain, and rebuild intimacy.

This article will walk you through why sexual health is affected in IC/BPS, how pelvic floor dysfunction and the nervous system play a central role, and what you and your partner can do to move forward with confidence and hope.

Why Sexual Health Matters in IC/BPS

Sexual health is not just about intercourse, but about connection, pleasure, confidence, and feeling safe in your body. When IC/BPS symptoms are present, sexual health often becomes complicated by pain during or after intimacy, fear of triggering symptoms, increased pelvic muscle tension, reduced desire, and emotional distress that can lead to avoidance.

Over time, these experiences can create a reinforcing cycle where pain leads to fear, fear leads to avoidance, avoidance increases muscle tension and nervous system sensitivity, and that increased sensitivity leads right back to more pain. Breaking this cycle is one of the most important steps toward improving quality of life, and it is absolutely possible with the right approach.

The Real Driver of IC/BPS Symptoms and Sexual Pain: Pelvic Floor Dysfunction

One of the most important and often overlooked contributors to sexual pain in IC/BPS is pelvic floor dysfunction.

The pelvic floor muscles sit at the base of your pelvis and play a critical role in bladder function, sexual function, core stability, and how your body processes and modulates pain. In people with IC/BPS symptoms, these muscles are very commonly overactive, guarded, and tender, even when the symptoms feel like they are coming from the bladder.

This distinction matters because the vast majority of people with IC/BPS do not have true bladder pathology.

Research shows that fewer than 10% of patients have Hunner's lesions, which are the primary identifiable bladder-specific finding, and in people under the age of 50 that number drops to less than 4%. What this means is that while symptoms can feel like they are coming from the bladder, they are most often being driven by pelvic floor dysfunction and nervous system sensitivity.

When the pelvic floor muscles are tight and overactive, they can create pain with penetration, aching or burning after intimacy, difficulty relaxing during sexual activity, and reduced pleasure or arousal. Even if symptoms initially began as urinary urgency, frequency, or pelvic discomfort, the pelvic floor often becomes involved over time and can continue to perpetuate symptoms independently and affect sexual health.

The Overlap Between IC/BPS and GSM

Another important and often overlooked contributor to sexual pain is Genitourinary Syndrome of Menopause (GSM), which can occur during perimenopause, menopause, or even postpartum (called genitourinary syndrome of lactation or GSL) or as a result of prolonged use of hormonal birth control.

GSM and other hormonal changes near the urethra and vaginal opening can lead to vaginal dryness, tissue thinning, irritation, burning, and discomfort with intercourse, along with urinary symptoms such as urgency and frequency that can closely mimic or overlap with IC/BPS. Because these symptoms can look so similar, GSM and other local hormonal factors are sometimes missed, which can delay effective treatment.

Addressing tissue health is a key component of care, and for many patients, local vaginal estrogen can significantly improve tissue quality, increase elasticity, reduce irritation, and make intimacy more comfortable. When combined with pelvic floor physical therapy and nervous system regulation, this can be a powerful part of a comprehensive treatment plan to enhance your sexual health and well-being.

The Nervous System and Central Sensitization

Another key piece of the puzzle is how the nervous system adapts over time.

With chronic symptoms like those seen in IC/BPS, the body can develop central sensitization, which means the nervous system becomes more sensitive and more efficient at producing pain signals. This can result in pain being felt more intensely, pain occurring with less provocation, and the body having difficulty "turning down" those signals once they start.

In the context of sexual health, this means that the brain and body may begin to associate intimacy with danger or discomfort, even if there is no ongoing tissue damage. The anticipation of pain alone can lead to protective muscle tightening, increased vigilance, and a heightened pain response. This is not psychological weakness or something you are imagining, but rather a very real and well-understood physiological response that can be retrained with the right interventions like pelvic floor physical therapy to address both the sexual health symptoms and the underlying pelvic floor dysfunction that may be driving them.

Sexual Intimacy Is More Than Intercourse

It is important to recognize that sexual intimacy does not always mean penetrative intercourse, and for many people navigating IC/BPS, expanding the definition of intimacy can be both healing and empowering. Physical closeness, touch, arousal, and emotional connection are all meaningful parts of sexual health, and all of these can be impacted by pain or fear.

Even without penetration, people of any gender can experience pain during arousal, discomfort with touch, or fear-based guarding responses driven by the nervous system. When the body has learned to associate intimacy with pain, it may respond with tension, hesitation, or avoidance regardless of the specific activity. Understanding this helps shift the goal away from "just getting through intercourse" and toward rebuilding a sense of safety, pleasure, and connection in whatever way feels right for you.

Sexual Health in Men with IC/BPS and Chronic Pelvic Pain

Although IC/BPS is often discussed in the context of women's health, men can experience very similar symptoms under diagnoses such as chronic prostatitis or urologic chronic pelvic pain syndrome.

Men with these conditions may experience pelvic pain, urinary urgency and frequency, and sexual health concerns including painful erections, testicular pain, and pain with or after ejaculation. Just like in women, these symptoms are frequently driven by pelvic floor muscle dysfunction and nervous system sensitization rather than a primary issue with the prostate or bladder itself.

The same patterns of muscle tension, guarding, and fear avoidance can develop, and the same cycle of pain and anticipation can impact sexual confidence and intimacy. Recognizing that these symptoms have a musculoskeletal and neuromuscular component is critical, because it opens the door to effective treatments like pelvic floor physical therapy that address the true drivers of dysfunction.

Sexual Health, Pelvic Floor Dysfunction and IC/BPS

Many people navigating IC/BPS and sexual pain share similar concerns, and understanding what is happening in your body can be incredibly empowering.

Pain with sex is rarely caused by a single factor and is

much more commonly the result of a combination of pelvic floor muscle tension, nervous system sensitivity, and, in some cases, changes in tissue health influenced by hormones. When symptoms flare after sex, it is not because intercourse is damaging the bladder, but rather because the pelvic floor muscles may become more tense or irritated and the nervous system may amplify signals, which can then be perceived as bladder-related symptoms.

Fear of intimacy is also extremely common, especially if previous experiences have been painful. While avoiding sex can feel protective in the short term, it often reinforces the brain's association between intimacy and danger, which can make returning to pain-free intimacy more difficult over time.

Challenges in relationships are another frequent concern, as partners may feel confused, rejected, or unsure how to help, while the person experiencing pain may feel guilt, pressure, or a sense of isolation. These dynamics are incredibly common, and they can improve significantly with better understanding and communication.

The Role of Pelvic Floor Physical Therapy

Pelvic floor physical therapy is one of the most effective, evidence-based approaches for addressing both IC/BPS symptoms and sexual dysfunction, and it remains a first-line treatment recommended by the American Urological Association Guideline, which was updated in 2022. Pelvic floor physical therapy can address all symptoms of IC/BPS because it addresses the full picture rather than just one piece of the puzzle.

A trained pelvic floor physical therapist works to reduce pain by using hands-on techniques to release muscle tension and address areas of tenderness in the pelvic floor, while also helping retrain the pelvic floor muscles to relax, coordinate, and function normally during both daily activities and intimacy. Treatment also includes education about how pain works in the body, along with strategies to calm an overactive nervous system and reduce central sensitization.

Importantly, pelvic floor physical therapy directly supports a return to sexual activity by guiding a gradual and supported progression back to intimacy, helping patients find comfortable positions, introducing tools such as dilators or vaginal trainers when appropriate, and building confidence step by step. This process is not just about reducing pain, but also about restoring pleasure, improving arousal, and helping you feel connected to your body again in a positive way.

Just as importantly, this work helps reduce fear and avoidance by creating a sense of safety and control, which is essential for long-term improvement in both symptoms and sexual health.

Rebuilding Intimacy: A Team Approach

Sexual health is deeply relational, which means that healing often involves both partners.

If you are the one experiencing symptoms, it is important to communicate openly about what you are feeling and to begin redefining intimacy in a way that does not center solely on penetration, while also allowing yourself to move at a pace that feels safe and sustainable.

For partners, understanding that the pain is real and not a reflection of rejection is essential, and removing pressure or expectations around performance can help create a safer space for connection while fostering trust and empathy.

When both partners approach this as a shared challenge rather than an individual problem, it creates an opportunity not only for physical healing but also for a deeper level of emotional connection.

When and Where to Seek Help

If you are struggling with sexual pain, fear around intimacy, or changes in your sexual health related to IC/BPS, seeking the right support can make a profound difference.

Pelvic floor physical therapy should be the first place to start, as it has the highest level of evidence support in clinical guidelines and directly addresses the underlying drivers of symptoms, including muscle dysfunction and nervous system sensitization, while also providing a clear and structured path back to not only pain-free intimacy but also pleasurable and fulfilling sexual experiences.

In addition to pelvic floor physical therapy, working with a medical provider can be helpful when indicated, particularly for options such as vaginal estrogen to improve tissue health or muscle relaxant suppositories that can reduce pelvic floor overactivity. For some individuals, a pain management specialist can also play a role in helping calm an overactive nervous system and reduce the intensity of pain responses.

Mental health support is another critical component, especially with providers who specialize in sexual health or couples therapy, as they can help address fear avoidance patterns, anxiety, and relationship dynamics that often accompany painful sexual experiences. These specialists can also support both partners in navigating communication, expectations, and the emotional impact of chronic pain on intimacy.

A Final Word: There Is Hope

Living with IC/BPS can make it feel like your body has turned against you, especially when it affects something as personal and important as sexual health. However, the symptoms you are experiencing are understandable, they are treatable, and they do not define your future.

By addressing the true drivers of symptoms, including pelvic floor dysfunction, nervous system sensitization, and tissue health, it is possible to reduce pain, rebuild confidence, and restore intimacy in a way that feels safe and empowering.

For partners reading this, your role matters deeply, and

your empathy, patience, and willingness to understand can make a profound difference in the healing process.

You are not alone in this, and with the right support, things can get better.

Dr. Nicole Cozean, PT, DPT, WCS, is the founder and owner of PelvicSanity, a leading pelvic health and wellness center in Southern California known for its expert, patient-centered approach to care. She is also the author of The Interstitial Cystitis Solution, which has helped thousands of patients better understand and overcome pelvic pain and IC/BPS symptoms. In addition to her clinical work, she is the founder of Pelvic PT Rising, a global educational platform dedicated to helping pelvic health practitioners elevate their clinical skills, confidence, and impact. Dr. Cozean is also the co-founder of PelviCon, a premier national conference designed to advance the field of pelvic health through collaboration, innovation, and high-level education. She was named the 2017 Physical Therapist of the Year by the Interstitial Cystitis Network and the 2012 Chapman University Alumnae of the Year. She is also a former ICA Board member.

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IC, Couples, and Intimacy

Jill Solomon, MFT, discusses how intimacy can remain possible—and how couples can sustain the spark.

Jill Solomon, MFT, has been a licensed marriage and family therapist for 25 years. Practicing in the West Hollywood area of Los Angeles, Solomon has IC/BPS and endometriosis and specializes in working with patients and couples with chronic pain issues. She spoke with *ICA Update* about the challenges patients and their partners face, techniques for responsive arousal, and where couples succeed—and struggle—with intimacy. Learn more about Solomon at www.jillsolomonmft.com.

How does IC impact intimacy, and what can people do about it?

Interstitial Cystitis can absolutely have a profound effect on one's sex life. That is undeniable. With IC and pelvic pain, one can feel "broken" or experience a sense of loss around their femininity or viability as a partner.

Couples can do a lot about this. They can use these obstacles as an avenue for deeper growth and creativity in their sex life together. I have seen couples explore and express so much creativity despite limitations.

What I recommend is open, honest communication, lots and lots of talking, and making room for difficult feelings. Couples can wake up desire again and still acknowledge, "Yes, this is hard. I have deep grief about what has been lost together, but let's look at what we can do together to make each other feel wanted and loved rather than what we can't do."

Flirting, talking, touching, and designating time for intimacy can help couples bring back playfulness and fun together and help them redefine their intimate life together.

What are the challenges for couples?

There are many challenges couples face when dealing with a chronic illness together. The person who has the chronic illness may feel broken and have a lot of guilt and shame about not being able to satisfy their partner or not feeling well often. The pain is invisible, and this presents another issue for folks with IC and their partners. They often have to show up for work, for their kids, smiling through family dinners or kids events while they are writhing in pain. There is a lot of pushing through for folks who have chronic pelvic pain. As the saying goes, " I am not faking illness, I am faking wellness." That goes on a lot for those with IC.

I remember getting my graduate degree while my IC was at its worst. I think about the level of pain I was in for a decade and wonder how I got through that. IC patients are really warriors, as are their partners.

The partners of folks that have chronic pain may be dealing with caregiver burnout. They often have their own grief and loss seeing their partner in so much pain and also feel guilt and shame around their own healthy sexual needs and desires. They may feel short changed and need acknowledgment around what they are going through as well. It really can be a complicated issue with a lot of guilt, shame, frustration, anger, and burnout on both ends. Communication is key.

How can couples reach that understanding?

Couples can reach each other by gently and carefully having hear another person's perspective that may be vastly different from your own is vitally important and also equally challenging for most people. Both parties are struggling and suffering in different ways. When a couple is tackling chronic illness as "us against the problem" rather than one person solely responsible for their limitations, a lot opens up.

"Chronic illness challenges couples in ways that can lead to a lot of deeper understanding and believe it or not, passion. Love can really transcend a lot of the suffering that happens with chronic pain and illness. I feel hopeful for the couples I work with."

There is so much depth that can happen between a couple tackling illness in this way. "In sickness and in health" isn't just a trite saying. Chronic illness challenges couples in ways that can lead to a lot of deeper understanding and believe it or not, passion. Love can really transcend a lot of the suffering that happens with chronic pain and illness. I feel hopeful for the couples I work with.

What does understanding look like in practice?

There are specific techniques that I use that can help couples listen to one another well. I use the Gottman Rappaport Intervention by relationship-focused psychologist and author John Gottman (bit.ly/GRI26). Each person tries to hear the other and tune into their world without an agenda. The point is to fully hear your partner's perspective, ask open ended questions. and empathize and validate one another. This intervention isn't a one-time thing, it is something couples practice over and over again.

The more talking you do, the better when it comes to chronic illness. Open communication is vital and trying not to hide one's pain or desire is especially important. In therapy, couples learn how to redefine intimacy more broadly as well. Telling the truth about where you're at both in the bedroom and out of the bedroom is essential. I help couples feel more comfortable to do that.

How do you work with couples on issues around intimacy?

People often compare themselves to Hollywood romcoms where sex looks like two beautiful people ripping each other's clothes off. Every couple, whether they have a chronic pain condition or not, think that other people are having more sex than they are having. Every couple gets to define what works for them, and there is no right or wrong.

Sometimes it is not about this hot and heavy spontaneous desire we see in the movies. It can be a more intentional and thoughtful experience that even includes scheduling intimacy time. Intimacy could mean anything from holding hands, cuddling, taking a shower or bath together, or massaging one another or sex. Couples get to define what intimacy means to them.

The loss of spontaneity that can come with IC can weigh on couples. I think couples can integrate deep breathing or meditation together, more foreplay or less, shorter, gentler encounters, and playing around with different positions if penetrative sex is on the table. If not, enjoying all the other amazing things a couple can do that does not include penetration can be equally satisfying. The main thing that is important is that intimacy doesn't feel pressured or outcome/orgasm focused. Playing together is really important.

Where do couples get stuck when trying to restore intimacy?

Some couples get stuck at the very beginning because they aren't comfortable talking about desires, likes, dislikes, and boundaries. I have had clients so resistant to speaking about sex that they have told me they'd never return if I continued to ask about their intimate life.

Everyone's life story is different, and each couple gets to write a unique story of intimacy together. It can be helpful to create a safe space that is light and playful that doesn't have to be so heavy and serious. Living in chronic pain and having IC can be soul destroying at times. I think shame and fear can perpetuate stuckness in couples. Chronic illness brings up our deepest insecurities and shame. Allowing yourself to be seen and vulnerable is powerful. Couples that can share what they want or don't want intimately—not what they should want—may find it liberating. People can get stuck in the shame and fear of being judged.

How can therapy or counseling be helpful?

I think having a third party that can normalize these conversations can be immensely helpful. It is important to find someone who is comfortable talking about sex and facilitating difficult conversations about desire, shame, guilt, pleasure and pain.

"Chronic illness brings up our deepest insecurities and shame. Allowing yourself to be seen and vulnerable is powerful. Couples that can share what they want or don't want intimately—not what they should want—may find it liberating. People can get stuck in the shame and fear of being judged."

Therapists can provide communication tools and create a safe space for important and challenging conversations to happen together. It is an invaluable part of the equation when confronting a chronic illness like IC. When couples lose sight of hope, therapists can help keep it alive.

What should people look for in a therapist?

A good fit is very individual. I suggest meeting or talking with several therapists before deciding on who to work with. I do think lived experience is helpful, but not necessary.

I think it is helpful to find a therapist that enjoys couples work, and that is an area of specialization. It would be helpful to find a clinician who has worked with chronic pain and illness, pelvic pain in particular. Professional experience with disabilities, training in sex therapy, couples certifications and somatic therapies as well as Pain Reprocessing Therapy (Alan Gordon's work or EAET by Dr. Howard Schubiner) can also be something to look out for when choosing a therapist.

You should expect openness, empathy, and warmth but also some practical tools and resources that can help the couple feel like they are really moving forward and feeling hopeful again. I often hear couples complain that their therapist just sat back and watched them fight without intervening. Having practical tools for repair and growth is essential.

How can people restore confidence in their bodies?

I think somatic techniques can help people gain confidence back. I do a type of therapy called PRT and EAET that

> "Everyone's life story is different, and each couple gets to write a unique story of intimacy together. It can be helpful to create a safe space that is light and playful that doesn't have to be so heavy and serious."

helps people with chronic pain let go of fear and retrain the brain away from pain.

When you begin to interpret body symptoms as safe, it can break the pain/fear cycle. Meditation, gentle walking, and exercises can also restore trust in their bodies.

What are the differences in the couples who are successfully able to resolve their issues around intimacy?

Couples that have the ability to tolerate differences and repair with one another do better. They love each other way beyond the physical and are flexible in their ideas and beliefs. These couples genuinely care about each other's needs and feelings. They have the ability to repair and accept limitations with one another.

What should couples with IC remember?

They should remember that there is hope of having a rich, satisfying, and creative sex life regardless of limitations. With IC, there may be periods of remission as well as flare ups and periods of relapse.

It is best not to compare yourself to another couple's sex life. Let go of "shoulds" around intimacy. Maintain flexibility, and this can help you both redefine and broaden your idea of intimacy. Don't forget to keep playing together.

Online IC Resources

- **ICA Website:** ichelp.org
- **ICA Email:** icamail@ichelp.org
- **ICA Online Support Community:** ichelp.org/online-support-groups/
- **ICA Store:** bit.ly/ICA-store
- **Facebook Page:** facebook.com/InterstitialCystitisAssociation
- **YouTube:** youtube.com/ICHelp
- **LinkedIn:** linkedin.com/company/interstitial-cystitis-association
- **Instagram:** instagram.com/icahelp/
- **ICA News & Communications:** ichelp.org/icacommunicationssign-up/
- **ICA Webinars:** ichelp.org/videos-webinars/
- **Get the Facts:** ichelp.org/newly-diagnosed-toolkit/
- **Find a Healthcare Provider:** ichelp.org/healthcare-provider-registry
- **ICA Support Groups:** www.ichelp.org/living-with-ic/support-community/ica-support-groups/

Beneath The Skin

By Chrissy Richter

Like a tattoo, interstitial cystitis doesn't tell its whole story at once. I could see the early outlines forming long before I understood them. I stopped taking bubble baths as a child, though I don't remember why. Urinary tract infections became common enough in college that I learned to expect them, treat them, and move on. I didn't realize something deeper was taking shape. Recurring symptoms became normalized because they were familiar, not minor. Treatment was efficient and unquestioned. The goal was to stop the pain, not ask why it kept returning.

My symptoms began to shift in my twenties. Intermittent discomfort became more intrusive and personal. Intercourse became painful. I treated it as something temporary to work around. I didn't think to connect bladder symptoms with pelvic pain or intimacy. I assumed discomfort during sex was normal or somehow my fault. It began to shape my relationship with my husband in ways neither of us understood.

It wasn't until I mentioned "painful intercourse" during an OB-GYN appointment that the trajectory changed. That single detail altered the course of my care. A pelvic ultrasound was ordered. A cystoscopy followed. My symptoms were no longer being managed in isolation—they were being investigated.

I was newly married and had just begun graduate school. Life was moving forward quickly, but my body remained an unresolved question. I underwent the cystoscopy in September of 2008. The doctor explained the results while I was still groggy and disoriented from anesthesia. I don't remember what she said, just feeling that something important had been decided without my participation. Interstitial cystitis entered my medical record. It wasn't introduced as a turning point or a moment of clarity. It was simply documented, named, and largely unexplained. The diagnosis existed, but guidance did not. I was also diagnosed with irritable bowel syndrome, and I developed nerve pain that stretches from my ribs to the tops of my thighs.

On the anniversary of my mother's death, I had her handwriting inked on my forearm. The nerve pain from

my bladder flare was worse than the actual pain of the tattoo needle. I lived with pelvic floor dysfunction as well. Anxiety and depression shaped, in part, by the unpredictability of my body. Each diagnosis was like its own separate ink cartridge.

Over the years, I worked with six different pelvic physical therapists. Each relationship was intimate in a way that's difficult to explain unless you've experienced it: telling the same story again, trusting someone with a deeply private part of your body, allowing internal work that requires both physical and emotional vulnerability. During my first PT experience, I was pregnant with my son. He kicked in response to the pressure and movement. It was unexpectedly sweet—a reminder that even in pain, the body holds connection. When that therapeutic relationship ended, starting again with someone new felt heavy. Those relationships often ended without closure. Therapists would move on, and by the time I returned to therapy, they were simply gone. Each new beginning required retelling the story, reestablishing trust, and reopening places that were already tender. It felt cumulative—leaving impressions that were necessary, sometimes healing, but never fully erased. Pain has a way of fixing memories in place because they change what comes next.

Flares followed patterns I learned to recognize: hormonal changes, medication adjustments, dehydration, and altitude. Each its own distinct trigger, not unlike a tattoo artist's gun. At our family cabin in the Colorado mountains, those patterns were especially clear. While my husband and son snowboarded, I often found myself in the bathtub, trying to calm a flare. Even in moments of beauty and privilege, IC shaped how I participated. Support didn't eliminate pain; it made it survivable.

> "Methaphorical flinching and wincing as the needle pierces the skin... Some marks change the body forever. The hardest part is learning how to live gently inside them."

Interstitial cystitis is an invisible disability. During flares, my abdomen becomes swollen and distended—often referred to as "IC belly." I've had someone congratulate me on being pregnant when I wasn't. In those moments, I wished for a visible marker, something that would spare me the effort of explaining or correcting assumptions. Instead, I make daily decisions about what to disclose, what to endure privately, and what to let pass. What isn't seen still leaves its mark.

Alongside pain, I carried guilt. I told myself stories shaped by shame and the belief that bodies are supposed to tolerate discomfort if we've somehow earned it. I wondered whether I had caused this. Whether it was punishment for drinking alcohol, loving coffee, having sex, and enjoying food. When I decided to have a planned C-section because of my IC, I felt I had failed some unspoken test of strength. Even care itself sometimes felt indulgent. I've come to recognize these thoughts as part of the condition itself—not personal failures, but responses to living in a body that requires ongoing attention. Metaphorical flinching and wincing as the needle pierces the skin. Guilt doesn't make the pain easier to live with. It only makes it lonelier.

I am acutely aware that I am lucky. I have a deeply supportive husband, wildly understanding friends, and the flexibility of being a stay-at-home parent. It makes living with IC more manageable. At the same time, not contributing financially to my household carries its own weight. That awareness is why advocacy matters to me. I volunteer as an advocate for the Interstitial Cystitis Association because I want people with IC to be believed sooner, guided more clearly, and treated as whole people rather than a collection of symptoms.

Living with interstitial cystitis has taught me that what we carry doesn't have to be visible to be real, and it doesn't have to be heroic to be meaningful. My story isn't about overcoming pain. It's about learning how to live honestly inside a body that asks for care, attention, and understanding. Some marks change the body forever. The hardest part is learning how to live gently inside them.

Chrissy Richter is a volunteer ambassador for the Interstitial Cystitis Association and an advocate for community members living with IC/BPS. She lives with her husband and son in Denver, Colorado, where she enjoys photography, gardening, crafting, and supporting others through community connection.

No Soap: The Story of IC and Me

By Connie Passalacqua Hayman

1981 was simultaneously the best and worst year of my life. It was the year I began my career as a professional journalist, proudly named editor of a soap opera fan magazine called *Afternoon TV*. It was also the year I was diagnosed with interstitial cystitis, then a little-known disease.

Covering the soap opera beat for a national magazine was a dream come true, and I threw myself into it with an enthusiasm that is still strong after all these years. The job led to others and eventually to national syndication as I sought to be the first with the latest on everything from casting to storylines, digging behind the cameras for news of couplings and uncouplings, both fictitious and real life. I interviewed celebrities and soap creators and network moguls, scoring bylines in *The New York Times, The Washington Post, USA Today*, and many others.

Always, IC was there in my private inner world, dogging my steps. Always, there was the pain, sometimes just dull and muted, often sharp and getting worse, disrupting the orderly functioning of my body, despite the application of every treatment known to medical science at the time.

IC broke into my world much the way breaking news so often interrupts the daily flow of soap opera's storytelling. The awful difference is that IC isn't just an annoyance. It really hurts.

This is the story of IC and me. Let's begin with the glamour.

I started watching daytime soaps as a lonely teenager. Both my parents worked full time. I'd love to come home from school, perch on my father's Barcalounger and, with a bag of potato chips, watch the three network soaps. I loved the characters. I watched every day, so they felt like real friends. There were 13 soaps then, with titles like "As the World Turns," "Guiding Light," "All My Children," and "One Life to Live." With a five day a week schedule, they were written to make viewers addicted. The strategy worked. I was hooked at a very young age.

Afternoon TV magazine chronicled the soap world monthly. As editor, I wrote the coverlines, did a monthly gossip column and, of course, interviewed soap stars. There were so many soaps in New York then. My

assistant and I went constantly to the studios to watch them being taped.

Three networks were then making money on the very profitable genre (it financed primetime TV), and they treated the soap press like royalty, showering us with show mementos, from T-shirts to expensive embroidered jackets. (I still have a leather "Days of Our Lives" jacket.) There were soap parties all the time, often in such renowned restaurants as the Rainbow Room on the roof of Rockefeller Center. These soirees were always loaded with soap stars and fueled by the snack we hungry soap scribes craved: shrimp, shrimp, shrimp!

In the early eighties, New York nightlife was at its peak. Through a contact I even got into the opening of Studio 54. Did I say nightlife? Of course, that's when IC, a nocturnal disease, made its first appearance, and it hasn't left since. A theater journalist boyfriend was on the press list for Broadway shows. We went to Broadway and off-Broadway openings and other events several times a week. The problem was my bladder would start to ache so much I never made it to intermission and had to take a cab home all the time. I was always in agony!

At the time, no one I knew had any idea what IC was. A urologist confirmed my diagnosis and told me not to eat acidic foods. Looking up a forbidden food list, I caught sight of a new group called the Interstitial Cystitis Association. It was so great to know I was not the only one suffering from this terrible disease. That fall, the newly formed ICA had its first meeting at the United Nations. I went and met the woman who founded the organization, Dr. Vicki Ratner. I have supported and championed the ICA ever since. Forty years!

IC invaded my life with painful flares almost every time I went anywhere. But I was determined not to let it stop me. I graduated from soaps to writing about primetime and then-new cable TV. I was a columnist for United Feature Syndicate. My stories went to papers all over the country. Even when I was in dire bladder pain, I had to produce, produce, produce.

If you are a working journalist, you are on the run and interviewing people all the time. Getting through important interviews without interrupting many times to pee was always a problem. Yes, I had lunch with Omar Sharif (he kissed my hand). Charlton Heston invited me to talk to him while he washed his car on the set of "The Colbys." I interviewed a young Oprah Winfrey and Rosie O'Donnell, all the time having to go to the bathroom. It was worse when I was in pain, but a deadline is a deadline, and despite this awful disease, I did my job.

And of course, my ultimate interview story was nearly interrupted by a peeing accident. When he was the very popular host of "The Celebrity Apprentice" in 1997, I interviewed Donald J. Trump. He took me up in his helicopter and gave me a three-hour tour of Manhattan. Somehow, I got through those three hours without peeing. And The Donald was a real nice guy. It was a once in a lifetime tour, but I was very happy when the wheels set down on the runway again. I'd bet Mr. Trump had never heard of IC. Now that he is President, wouldn't it be great if he would use his influence to do something to alleviate our suffering?

Through the glamour of celebrity interviewing, there was persistent pain and the treatment it required. I went to a renowned urologist on Long Island initially. Then I started having bladder installations. Oy! What a hassle. After the treatment I would have to run home and pee (I had more than one urinary accident.) I met a nice man named Edward Hayman, who helped transport me to my doctors to get my treatments. He was very understanding of this disruptive disease. We were both journalists and adjunct professors of journalism at New York University. Eventually, we got married. His constant kindness in helping me when I am in IC pain continues. For both of us, IC has been a lifelong sentence.

Eventually, IC impeded my career. In 2015, I had a terribly painful flare combined with a very painful rectal fissure. I had what was commonly called a "nervous breakdown" and didn't work or write for six years. Only my husband and a beautiful beagle boy named Nigel Barthomow-Smythe (named after a soap opera character) got me through this period of pain and horror.

"I interviewed a young Oprah Winfrey and Rosie O'Donnell, all the time having to go to the bathroom. It was worse when I was in pain, but a deadline is a deadline, and despite this awful disease, I did my job."

I finally met a wonderful and kind urologist who really understood IC. He prescribed painkilling drugs (then

legal) which were a big, big relief. And he performed an operation on me, installing an InterStim device in my back. It has helped ever since.

How did I cope with IC all these years? First of all, I educated a lot of sympathetic friends. And I never, ever, ever go off the IC diet. This diet impacts just about everything I eat, but I find being strict with it the chief way of avoiding or at least reducing the pain. I'm Italian and as you know, tomatoes and tomato sauce is central to the Italian diet. No red sauce—it's full of acid—OMG! Now I make everything with imported yellow tomato sauce. I can only eat white pizza. And my yellow sauce lasagna is so good it even won over my future Midwestern in-laws.

"I never, ever, ever go off the IC diet. This diet impacts just about everything I eat, but I find being strict with it the chief way of avoiding or at least reducing the pain. I'm Italian and as you know, tomatoes and tomato sauce is central to the Italian diet. No red sauce—it's full of acid—OMG! Now I make everything with imported yellow tomato sauce. I can only eat white pizza. And my yellow sauce lasagna is so good it even won over my future Midwestern in-laws."

I have had some very bad dustups over the years with IC. I used to summer on Fire Island. Once I had such a bad attack, I had to take a 60-mile cab ride home in the middle of the night and go to the hospital. As all IC sufferers know, most staff in the emergency room don't know anything about our disease and a visit to one is a waste of time. I once walked out of a busy city hospital in the middle of the night because no one had ever heard of IC and didn't know how to stop my pain—or even believe I had a bona fide disease.

And now when we sufferers have a flare, doctors are prohibited from prescribing opiates. I find this vastly wrong and almost insane given the level of pain I have had and continue to have. I once fell on crooked pavement and when I woke up in an emergency room, the doctors had installed a urinary bag without my permission. For almost a year, I had to struggle with a urine bag attached to my ankles. I had to keep waking up my sainted husband in the middle of the night to help me change it. What a disgusting year that was until I had the bag taken out. Barbaric is the word for the bag, and I wish it on no one.

Of late, I have participated in the latest IC treatment: pain management. Many of my friends go to it for pains in their back and it was recommended to me to be good with IC. Once a month, I go into Manhattan to see a doctor and have a catheter stuck into the thin skin of my hand and sit there for more than an hour as lidocaine is injected into my veins. (To my doctor's chagrin, I always scream out loud when the catheter is inserted into my hand. It really hurts.) And the doctor often misses—I had blood all over my new blue jeans the last time I was infused. I've found this uncomfortable treatment moderately effective, but you have to keep on going back and back.

Of course, there is no cure for IC. However, there should be a better way to treat sufferers like us. I've found being constantly in pain very debilitating. I wonder what my life would have been like if I didn't have this terrible handicap.

Early on, I discovered the message boards on the ICA website and participated in them. That other people have this dreadful incurable disease and learn to cope with it means a lot to me. Thank goodness for the help and solidarity of the ICA! It and its supportive members have helped me *so* much over the last 40 years!

Connie Passalacqua Hayman has been a entertainment journalist specializing in daytime television for forty years. She was editor of Afternoon TV*, and contributed to many soap opera publications such as* Soap Opera Digest. *She wrote about daytime, cable, and primetime television for the United Feature (newspaper) Syndicate throughout the 80's and the 90's and for such publications as* The New York Times, USA Today, Variety, The Hollywood Reporter, Glamour*, and* TV Guide *and was the soaps columnist at* Newsday. *Since 2005, she has had her own website: Marlena De Lacroix: Soaps for the Thinking Fan (www.marlenadelacroix.com). She is a former adjunct professor of journalism at New York University and at Marymount Manhattan College.*

Selected research findings summarized in the recent issues of the ICA Research Digest. *To learn more and sign up for these monthly emails, visit* ***bit.ly/ICA-RD****.*

The Brain-Gut Axis, GLP-1s, and Chronic Pain

A recent article discussed GLP-1 medications and chronic pain conditions, suggesting that they may reduce inflammation in the nervous system and change how pain signals are processed in the brain and spinal cord, though this has mostly been shown in animal studies so far. These medications may also reduce pain sensitivity without losing their effectiveness over time, potentially leading to longer-lasting pain relief. The data is far from conclusive at this point, and additional studies are needed (Halloum W, Dughem YA, Beier D, Pellesi L. Glucagon-like peptide-1 (GLP-1) receptor agonists for headache and pain disorders: a systematic review. *The Journal of Headache and Pain*. 2024;25(1):112. https://doi.org/10.1186/s10194-024-01821-3).

Another article conducted a review of research on the brain-gut axis (BGA), which is emerging as a critical mediator in chronic pain, involving bidirectional communication between the central nervous system and the gastrointestinal system (Ho T, Elma Ö, Kocanda L, et al. The brain-gut axis and chronic pain: mechanisms and therapeutic opportunities. *Front Neurosci*. 2025;19:1545997, https://doi.org/10.3389/fnins.2025.1545997)

Sunobinop Phase 1B Study in Patients with IC/BPS

A recent study evaluated a new medication called sunobinop for IC/BPS. Instead of directly targeting the bladder, sunobinop modulates how pain signals are processed in the nervous system. The data come from a small, short-term human trial, but early results are promising across multiple IC/BPS phenotypes. In the study, 41% of patients reported meaningful improvement in bladder pain, urgency, frequency, and bladder capacity, compared to 9% in the placebo group. Sunobinop belongs to a new class of medications known as nociceptin opioid peptide (NOP) receptor agonists. As research continues, this class may represent a new direction in the treatment of IC/BPS. *—Kevin Blevins, BSN, RN, ICA Medical Advisory Council Member*

Social Media as a Source of Information on IC/BPS

A 2026 study examined how people discuss IC/BPS on social media platforms. The most concerning finding was that the vast majority of posts on both platforms lacked scientifically accurate information. Only about 9% of Instagram posts and 19% of Facebook posts contained reliable evidence-based content. The authors argue that healthcare professionals need to be more active on social media to provide trustworthy, easy-to-understand information for patients who turn to these platforms when looking for help with their condition. (Gubbiotti M, Gilli C, Pelizzari L, De Palma L, Rubilotta E, Rosadi S. Social media as a source of information on interstitial cystitis/bladder pain syndrome: support tool or misinformation? *Neurourol Urodyn*. 2026;1-7. https://pubmed.ncbi.nlm.nih.gov/42041193/)

Comparative Efficacy of Tadalafil and Amitriptyline in Female IC/BPS

A 2026 study tested whether tadalafil (a drug commonly used for erectile dysfunction) could help women with interstitial cystitis/bladder pain syndrome (IC/BPS). Researchers randomly assigned 132 women to one of three treatments: tadalafil alone, amitriptyline alone (a standard treatment), or a combination of both drugs at lower doses. Tadalafil and the combination were better than amitriptyline alone at reducing the frequency of daytime and nighttime urination and improving urine flow. About 85% of patients reported marked improvement by the end of the study. The authors recommended further studies with larger groups and longer follow-up. (Makled NN, Makled MN, Helmy TE, El-kenawy MR, El-Hefnawy AS. Comparative efficacy of tadalafil and amitriptyline in female interstitial cystitis/bladder pain syndrome: double-blind randomized trial. *Int Urogynecol J*. https://pubmed.ncbi.nlm.nih.gov/42096062/)

Association Between Depression Subtypes and IC/BPS

A study used Taiwan's national health insurance data to see whether different types of depression are linked to a later diagnosis of IC/BPS. After excluding people who already had IC/BPS or were diagnosed with it within six months of a depression diagnosis, the study found that people with recurrent depression and persistent/chronic depression were more likely to develop IC/BPS and tended to be diagnosed sooner than similar people without depression. People with single-episode depression did not show a clearly higher risk, although their time to diagnosis was still shorter. The authors conclude that long-term or recurring depression may signal higher IC/BPS risk and that earlier recognition and care for these depression types could matter, while also noting the limits of insurance-code data. (Chang KM, Lee MH, Chen YF, Wu SL. Association between depression subtypes and interstitial cystitis/bladder pain syndrome. *Int Urogynecol J*. https://pubmed.ncbi.nlm.nih.gov/41954772/)

Join the ICA's Angel Society — Become a Monthly Donor

The ICA is pleased to recognize our current members of the Angel Society. Be an ICA Angel with your convenient, tax-deductible monthly donation. Your recurring contribution will help sustain ongoing education, awareness, and advocacy for those living with IC/BPS. Join ICA's Angel Society online today! Your credit card will be charged the amount you designate on the same date each month, and you can change or cancel it at any time.

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5 Things: Reframing Intimacy

ICA Update *readers shared how they communicate about intimacy with their partners. Here are five common themes:*

1. HONESTY

"Staying calm and being honest about my pain. Also, I am mindful about communicating my physical limitations in a manner that does not suggest I am blaming or shaming my husband for restrictions I experience from IC."

"[Acting] in a way that is trusting and supportive (rather than allowing embarrassment, fear, criticism, or the like to take over). "

"Choosing the right moment to discuss things."

2. OPEN CONVERSATIONS

"A few years ago, I bought a box of cards with prompts on them for partners. The prompts help to start deeper conversations and therefore strengthen trust and intimacy in romantic relationships. It's been really fun and helpful for us to sit down together and go through a couple of cards together. In spite of being together for more than 30 years, we keep learning more about each other, which brings further ease with physical intimacy."

3. CUDDLING AND MASSAGE

"Cuddling in bed."

"Take time to give each other a soothing massage while in bed together. This can easily morph into finding ways to pleasure each other, and to have a fulfilling experience of intimacy, even if full intercourse isn't possible."

4. WRITING LETTERS

"When no intercourse is possible, we ... write letters to each other on what we would like to be doing physically if IC was not in the picture."

5. HUMOR

"Sprinkling in some humor definitely helps!"

INTERSTITIAL CYSTITIS ASSOCIATION

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What is the ICA?

The Interstitial Cystitis Association (ICA) is the only national nonprofit organization dedicated to improving the quality of healthcare and lives of people living with IC/BPS in the U.S.

Are You on the List?

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