INTERSTITIAL CYSTITIS ASSOCIATION

ICA UPDATE

Summer 2025

ICA

Conquering IC. Changing Lives.

40 Years

As we celebrate the ICA's 40th birthday, we look at the nonprofit's impact along with what's next.

A New Era for the Interstitial Cystitis Association

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

The donors are listed after the honorees and remembered loved ones.

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ICA UPDATE
Interstitial Cystitis Association

ICA
Conquering IC. Changing Lives.
Interstitial Cystitis Association

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IN THIS ISSUE

A New Era for the Interstitial Cystitis Association: Empowering Patients, Together.

The ICA is now proudly run by patients, for patients, which marks a significant shift in our approach. This patient-led leadership allows us to focus on the needs and desires of our community with unparalleled focus and empathy. We understand that living with IC/BPS can be isolating and often overwhelming. Our goal is to ensure that every individual grappling with this disease feels seen, heard, and supported.

One of our primary goals is to combat misinformation surrounding IC/BPS and empower patients through education. We are committed to developing more educational programs designed specifically for those living with IC/BPS. Our aim is to provide reliable, evidence-based information that helps patients make informed decisions about their health. We believe that when patients are equipped with knowledge, they can take a more active role in their healthcare journey, leading to better outcomes and improved quality of life.

In addition to enhancing our educational offerings, we are excited about the opportunity to foster a community where patients can connect, share experiences, and support one another. The importance of community in managing chronic illness cannot be overstated. Together, we can continue to build a network of understanding and encouragement that empowers individuals to navigate their healthcare journeys confidently.

As we are the only nonprofit in the U.S. for IC/BPS patients, our vision extends beyond just our community. We aim to be a trusted resource for individuals dealing with other chronic illnesses and chronic pain conditions. Our goal is to create a comprehensive platform where patients can find reliable information, share their stories, and access vital resources.

The path forward is bright, and we are eager to take this journey with you. We invite you to engage with us, share your thoughts, and become an active participant in shaping the future of the ICA. Together, we will build a more informed, empowered, and connected community.

As we step into this exciting new era, we remain committed to listening to your needs and advocating for your rights. We are here for you, and we look forward to creating meaningful change together. Thank you for being part of the ICA family!

ICA Welcomes New Board Members

On December 6, 2024, the ICA took a bold step towards better connecting with IC/BPS patients by becoming a patient-led and managed organization.

Fundraising efforts are being diversified, as the organization seeks additional, relevant corporate partners, along with both private and public grant opportunities. Additionally, donors will be provided with more objective information on where their dollars are going and how many patients are being assisted with every dollar donated. Patient education and awareness will receive an upgrade as well. The expert speaker series is now offered for free, and a research newsletter is being created so that patients can stay abreast of new clinical trials and research in language we can all understand (see below).

Amidst these changes, one thing will always stay the same: the ICA is dedicated to providing education, awareness, advocacy, community, and support to IC/BPS patients and will utilize evidence-based information whenever possible so that we remain your trusted source for IC/BPS information.

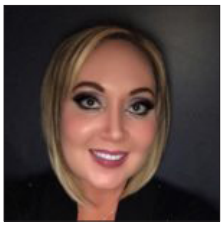
The ICA is also excited to introduce three new members of the ICA Board of Directors, as well as a new board chair and vice chair. These outstanding individuals have been chosen for their ability to lead, advise, and support our organization as it enters an exciting new chapter.

Holly Goodwin earned her master's degree in library and information science in 2018 and has since dedicated her career to academic librarianship. Residing with her partner in a small, rural southern town, she is also a passionate advocate for women with chronic pelvic pain, drawing from over 15 years of personal experience with IC/BPS and the challenges of finding effective treatment. Through her work with the ICA, she aims to empower others with the disease to find effective treatment with greater ease and speed.

Photo Credit: Grant Delin

Avery Singer is an artist living and working in New York, NY. She has been honored with solo museum presentations at Museum Ludwig, Cologne (2019); Kölnischer Kunstverein, Cologne (2017); Secession, Vienna (2016); Stedelijk Museum Amsterdam (2016); Hammer Museum, Los Angeles (2015–16); Fondazione Sandretto Re Rebaudengo, Turin (2015); and Kunsthalle Zurich (2014–15). Singer's work is represented in the permanent collections of the Museum of Modern Art, New York; Art Institute of Chicago; Hammer Museum; Whitney Museum of American Art, New York; the Tate, London; and Stedelijk Museum Amsterdam, among numerous others.

Singer is a passionate advocate in the field of women's health, having been a chronic pain patient nearly all of her life. In addition to the ICA, she serves on the board of her alma mater, the Cooper Union of the Advancement of Science and Art, and philanthropically supports the work of the Endometriosis Foundation of America.



Amber Carter-Frauenhofer has been appointed as Chair of the ICA Board of Directors. Carter previously served as a passionate member of the board and the liaison to the ICA Medical Advisory Council before stepping into the role of vice chair.

As a long-time IC/BPS patient, Carter has found solace and motivation through engaging with and supporting other IC/BPS patients. She credits the ICA for consistently providing the valuable information and resources needed to navigate this complex disease. Carter plans to leverage her new role to further enhance knowledge and awareness about IC/BPS.

Callie Krajcir, RD, has been appointed as a new board member and its Vice Chair. A registered dietitian specializing in IC/BPS, she has helped over 100 IC/BPS Warriors get relief from their symptoms through diet and lifestyle interventions. Krajcir has a bachelor's of science in nutrition and dietetics from West Chester University and a master's of science in Clinical Dietetics from the University of Rhode Island. She has struggled with IC/BPS her entire life and currently has her symptoms managed through a holistic approach. She has been a Registered Dietitian for five years and during that time decided she wanted to help other IC/BPS Warriors get relief from their symptoms and improve their quality of life. Krajcir is the host of IC You, a podcast focused on raising awareness for IC and interviewing various experts in the field. She is also very active on social media platforms like Instagram and TikTok to share information on IC/BPS and raise awareness. Callie currently resides in Pennsylvania with her boyfriend, dog, and two cats. She enjoys traveling, taking barre classes, and watching Philly sports teams.

Learn more about the ICA Board of Directors at www.ichelp.org/about/board-of-directors/.

ICA Launches Research Digest

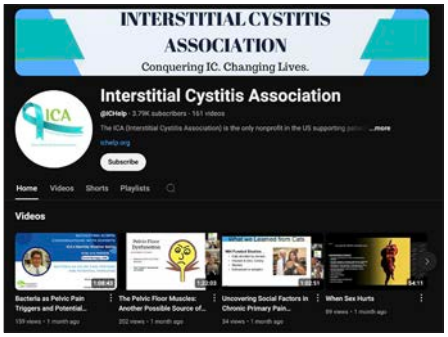

ICA Research Digest
Translating Science, Empowering Patients
March 2025 No. 1
Greetings from the inaugural ICA Research Digest!
I'm Dr. Laura Santurri, the Chief Operations Officer at the ICA, and I'm thrilled to introduce our very first Research Digest. This newsletter aims to translate timely and relevant scientific literature to equip our community with the knowledge needed to make the best possible decisions regarding their care.
As a public health professional, I am passionate about ensuring that the research literature is accessible to everyone. In addition, I also believe in the importance of ensuring that research results are not overgeneralized or used in ways that may take advantage of others (e.g., turned into oversimplified headlines that become "clickbait"). Research is complex, but that doesn't mean it can't be made understandable.
Each of the Research Digests will have summaries of recent studies that apply to those living with interstitial cystitis/bladder pain syndrome (IC/BPS), which includes research on common co-morbid conditions (i.e., other conditions that are common in IC/BPS patients). As always, I welcome feedback, questions, and ideas for studies you might like to see summarized here; you are welcome to reach out to me at laura.santurri@ichelp.org.
What's in this edition of the ICA Research Digest?
Quick Tip! - Being cautious of clickbait....1
Definition Spotlight - chronic overlapping pain conditions....2
Patient Question - Should I stop taking my Elmiron?....2
An Update on Pentosan Polysulfate Sodium (aka Elmiron) & Maculopathy....2
Recent Studies on Vulvodynia & IC/BPS....3
Quick Tip!
Above, I mentioned that, sometimes, results of studies are turned into "clickbait." This is when a media or story headline oversimplifies or exaggerates research findings to grab your attention. I always encourage everyone to read the full article or story before making a conclusion. Don't rely on headlines; they can be intentionally misleading!
WRONG WAY

The ICA has launched a new digest of research focused on IC/BPS and related conditions. The ICA Research Digest aims to translate timely and relevant scientific literature to equip our community with the knowledge needed to make the best possible decisions regarding their care.

"As a public health professional, I am passionate about ensuring that the research literature is accessible to everyone," says ICA Executive Director Dr. Laura Santurri, PhD, MPH, CPH, aPHR. "Research is complex, but that doesn't mean that it can't be made understandable."

To read the most recent ICA Research Digest, visit www.ichelp.org/living-with-ic/news-magazine/ica-research-digest/.

New IC/BPS Webinar Series, Video Educational Hub



In an effort to provide more meaningful educational access to the IC/BPS community, the ICA has announced that all webinars will be provided free of charge. Our new video educational hub, the ICA Channel on YouTube, includes recordings of all our new expert series webinars as they occur, and free recordings of all of our previous Expert series webinars. You'll also find short videos from our board members, MAC (Medical Advisory Council) members, and other experts with insight to share on all things IC/BPS.

ICA's new webinar series began in January with a presentation on research by ICA Executive Director Dr. Laura Santurri, followed in February by "MYPAICE: Mindfulness and Yoga for Pain with Interstitial Cystitis Evaluation" by Dr. Angela Dao and "Pain Reprocessing Therapy: Healing Interstitial Cystitis" by the Pain Processing Therapy Center in March.

Subscribe to the ICA Channel at www.youtube.com/@ICHelp.

ICA Partners with U.S. Pain Foundation for Support Groups, Updates IC/BPS Support Group Directory

The ICA has entered a new partnership with the U.S. Pain Foundation to provide the IC/BPS patient population with peer-led support around the country with a focus on mental health tools for pain management and resilience.

The U.S. Pain Foundation offers free online peer support groups through its program, Pain Connection. These groups are led by trained volunteer peer leaders and provide compassionate support and evidence-based education. Current groups include state-based, national, daily, and specialized populations. Visit painconnection.org/support-groups to learn more or register to attend a group. If you have any questions about this resource, email contact@uspainfoundation.org.

While many IC/BPS-specific support groups continue to operate around the county, this partnership allows the ICA to expand our reach and increase access for those living with or supporting those with IC/BPS. The ICA has also recently updated its support group listing page, available at www.ichelp.org/living-with-ic/support-community/us-support-groups/. If you're part of an active support group not currently listed, please reach out to us at icamail@ichelp.org. Together, we can continue to foster a supportive environment for everyone affected by IC/BPS.

Spread the Word to Raise Awareness About IC/BPS

You can make a significant impact by printing this informational flyer and taking it to your doctors' offices or emailing it to them and asking them to display it prominently—even in the bathrooms. By spreading the word, you can help others receive a faster diagnosis and better treatment. Let's work together to make a difference!

View and download the flyer at www.ichelp.org/wp-content/uploads/2024/08/ICA-Printout-for-Doctors-Offices.pdf

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Together For Tomorrow: 40 Years Strong

Last fall's IC/BPS Awareness Month event was a tremendous success, with 320 participants coming together to support the cause and benefit from valuable educational content, including weekly newsletters and two live webinars offering valuable insights and support.

ICA raised $6,172, thanks to the generosity and dedication of our community. However, we have a way to go to reach our $20,000 match goal—which would bring us to $40,000 in support to commemorate ICA's 40 years of dedication to the IC/BPS community. There's still time to donate and fundraise! Every contribution, no matter the size, brings us closer to our target and helps us continue our mission.

Special recognition goes to our top fundraisers: Amber Carter, Nicole Mehall, and Claudia King. Their outstanding efforts have made a significant impact. We would also like to extend our heartfelt gratitude to our sponsors for their incredible support during ICA Awareness Month.

- Platinum Sponsor: Desert Harvest
- Silver Sponsors: Femetry and Prelief

Let's continue to work together to make a difference! To donate or create your own fundraiser, visit www.justgiving.com/campaign/ica40thanniversary.

IC Awareness Month Proclamations

New IC Awareness Month proclamations have been secured in several states and cities, including Texas, Oklahoma, Louisiana, Georgia, Ohio, Maryland, Connecticut, Virginia, New Jersey, Illinois, and Colorado, as well as the cities of Orlando, Florida, and Denver, Colorado.

"After almost 30 years of living with this disease, I finally feel validated," Becky Pelicano Avery posted on social media after receiving a copy of Virginia's proclamation in the mail.

This recognition highlights the importance of raising awareness for interstitial cystitis/bladder pain syndrome (IC/BPS) and the efforts of the IC/BPS community. Proclamations help bring attention to the challenges faced by those affected by IC/BPS and emphasize the need for continued support and research. The ICA, with the support of the IC/BPS community, worked hard to achieve this recognition and our efforts are making a difference in increasing visibility and understanding of the condition. This success sets a strong foundation for future advocacy and awareness initiatives.

"One step closer to bringing awareness to this painful illness," Gina Cafone said after receiving the proclamation letter for the state of New Jersey.

To learn more about proclamations and how you can request one in your city or state, visit www.ichelp.org/get-involved/advocate/ic-proclamation-requests/.

Order Your 40th Anniversary Merch Now!

Shirts, hats, hoodies, coffee mugs—even a tote bag. Featuring winning designs from ICA's 40th anniversary logo contest, these items commemorating ICA's milestone are available online. Visit www.bonfire.com/store/interstitial-cystitis-association/ for more.

40 Years, 40 Voices

The ICA's four decades of support, advocacy, and community, in the words of those who were there.

Forty years ago this spring, Vicki Ratner, MD, went on ABC's *Good Morning America* to discuss what was considered by doctors—if it was considered at all—a rare and possibly psychosomatic condition. Mailbags of letters from others with the same confounding symptoms soon followed, and the fledgling organization that Dr. Ratner had founded the previous summer in her New York City apartment soon blossomed.

To commemorate the 40th anniversary of the Interstitial Cystitis Association, *ICA Update* reached out to many of the people who were instrumental in the organization's success over the decades—leaders, advocates, practitioners, volunteers, and patients. Here are their thoughts, in their own words.

THE EARLY YEARS: Starting Small, With a Big Impact

Dr. Vicki Ratner, ICA founder and president emeritus

We had to get started very small, and what really helped was the media. We were fortunate to get on *Good Morning America* and a lot of the women's magazines, radio, and newspapers like the *New York Times*. That did not come easily, nor did it come quickly. We got a lot of answers on postcards like "not for our audience." I should have saved them—it was very discouraging at first (see more, p. 13).

Kathy Jolowicz, ICA founding member

As one of the five women who met that first day with Dr. Vicki Ratner in June of 1984, in her apartment, we launched the beginning of the ICA. I ran some support groups, receiving horror stories and hearing of suicides, broken marriages, loss of jobs, anger, yelling, hysteria, and helplessness. Doctors threw us out of their offices, and my internist gave me the phone number of a psychiatrist, which I tore up.

Barb Zarnikow, former ICA board chair

We would go to [medical] conventions, and some doctors would go by and do the crazy thing with their fingers around their ears.

Jill Peters-Gee, MD, ICA Medical Advisory Council member

In 1985, just one year after the ICA was established, I began my journey as a urologist. At that time, IC was a condition shrouded in mystery, often misunderstood and misdiagnosed. There was little research, scant treatment options, and almost no public awareness.

I vividly remember meeting Dr. Ratner in August 1987 at the NIDDK Consensus meeting in Bethesda, Maryland. It was a time of burgeoning awareness and hope for those of us determined to uncover the truths about IC.

Naomi B. McCormick, Ph.D., clinical psychologist

I have had IC for 53 years but wasn't diagnosed correctly until I consulted a urologist in the late 1980s. My urologist gave me information about the ICA, then a grassroots organization, and collaborated with me on research. Dr. Vicki Ratner and other leaders, each of whom was an accomplished professional who had IC, were quick to welcome me. My location made easy to meet with the leadership team, many of whom lived on the East Coast, and collaborate on planning conferences, providing support and education for other patients, and writing articles. During the 1980s and 1990s, I presented at several ICA conferences and met the physicians who were advocates for IC patients and were doing groundbreaking research. These urologists were friendly and caring, generously sharing words of wisdom with us as their friends and collaborators.

Rhonda Garrett, former ICA information specialist

I started volunteering for the ICA in 1998. I had just been diagnosed, and my urologist gave me brochures about the ICA which included a long list of volunteer opportunities. Within a year, my Kansas City support group went from 6 people to 300. The need was so great for information and support! People who called the ICA for information spoke to women who offered understanding and information from their living rooms and mailed brochures out of their garages. It was an enormous undertaking that was mostly powered by people who suffered from IC themselves.

ADVOCACY: Driving Research, Understanding, and Support

Eric Zarnikow, former ICA board chair

ICA's most important role is advocacy. The money goes where there's attention, and without organizing patients to advocate, the research devoted to IC would be significantly less. ICA is the only organization that's organized people to advocate for support for research, as well as insurance coverage and Social Security disability benefits.

ICA provides a voice to the millions of people who have IC. There are a lot of invisible people out there suffering, and we're here to give them a voice—and hope.

Diana Dunn, volunteer advocate

The effort the ICA has made to educate the medical

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community has been critical. I lobbied with Dr. Ratner in the 2000s and greatly benefited from the work that Vicki did to get IC qualified for Social Security disability benefits. I think this may be understated and underappreciated. It was tremendous that Vicki had the foresight to fight for this.

Teri Cooper, volunteer advocate

The thing about going to Capitol Hill is that it's important when you're asking for money that people see what it's for. When they see the personal toll that IC/BPS takes, they're a lot more willing to back those kinds of requests.

Barb Zarnikow, former ICA board chair

The work on Capitol Hill has always been very impactful to me. I testified before a Senate committee about the Department of Defense's Peer Reviewed Medical Research Program (PRMRP). I talked to one senator afterwards who said, "this sounds like a terrible thing to have." None of this was easy. We'd be on the Hill trying to get support for IC with all these little kids with balloons [advocating for other causes]. We weren't as cute as the little kids, but we did our best.

Jeffrey G. Proctor, MD, urologist and Medical Advisory Council member

We need to get more treatments FDA approved. We need further advocacy to get additional drugs evaluated and approved by the FDA. The only FDA-approved oral medication is now in the FDA black box. That's why we need more advocacy for IC/BPS.

For several years, I did an IC awareness walk in my community. We must all collectively step up for IC to strive for a cure, and these events help us get there, one step at a time.

PERSONAL JOURNEYS: From Pain to Purpose

Laura Santurri, PhD, MPH, CPH, aPHR, ICA Executive Director

The ICA didn't just change my life; the organization saved my life. In 2000, after stumbling on some information about IC/BPS, I found the ICA. I spoke directly with one of their volunteers (thank you, Linda Salin!), and my life changed. After three years of living with debilitating symptoms and not knowing what to do or if there were others like me out there, I was able to locate a knowledgeable and kind medical provider, as well as a local support group that I eventually came to lead. What a relief it was to finally have a name for what I was experiencing and to know that there was an entire organization devoted to people just like me!

Carol Davis, IC/BPS patient

The ICA has been an invaluable resource on my IC/BPS journey. Knowledge truly is power, and understanding my condition has allowed me to "live well with IC" for over three decades. Becoming my own advocate and taking charge of my condition gave me a sense of control. I am fortunate to have a robust support system of family and friends who have helped me navigate this path with resilience and hope.

Theda Khrestin, former ICA board member

Being diagnosed with IC was both devastating and a relief. As anyone knows who has suffered without a clue as to what is going on, receiving a diagnosis can be liberating. But once I found out I had IC, I also soon found out there was no cure for the disease and very few effective treatments. I finally came across the ICA in an internet search. The ICA helped connect me with a doctor who was up on the latest treatments and prescribed me a combination of medications that finally provided real relief. Out of gratitude to the ICA, I decided to apply for the board of directors. It was at this juncture that I finally met my first fellow patient. After 11 years of suffering without understanding, I met Laura Santurri during my board interview and was jumping for joy inside because I finally met someone who understood what it was like to have IC!

Since joining the board, I have discovered that this autoimmune, chronic pain disease effects almost every patient in a slightly different way. I've discovered there is not a "zinger" solution to ending the pain or discomfort. I've learned that we all walk very different paths in life and deal with the disease in very different ways. Finally, I've learned that you have to laugh about some of the things you do and endure as an IC patient. I am eternally grateful to the ICA for the community it has surrounded me with and the knowledge I am now armed with about my own disease.

David Klumpp, PhD, researcher and ICA board member

Forty years of the ICA gives me much to remember. My mother was a longtime IC sufferer. Indeed, I recall her bladder becoming a life-changing problem in the early 1990s, but I confess being ignorant of the details then as a young male fortunate not to have concerns about the

urinary tract. This was the time before Viagra, when urologic issues were almost taboo. And particularly now knowing the general state of IC awareness — or lack thereof — it was possible my mother did not yet have a diagnosis, despite her many years as a highly trained ER nurse. Coincidentally, in 1998 I began working with Dr. Anthony Schaeffer, then-Chair of Urology at Northwestern and a leading researcher and clinical expert in UTIs and pelvic pain. Through this work and preparing my own grant application in response to an NIDDK funding initiative, I became aware of IC myself and mentioned it to my mother. To my own surprise, she exclaimed that she had mast cell-associated IC! Over the years, we would talk about her challenges managing flares, how badly she longed to again to drink a Diet Coke, or her painful memories of some of the early therapies she endured.

As my own research career in urologic sciences developed, I have been lucky to meet and even work with many leaders in clinical IC, IC research, and IC patient advocacy, including participants in the seminal 1987 NIDDK workshop that culminated in the consensus criteria for diagnosis of IC. I even had the privilege of serving on NIDDK panels with Dr. Vicki Ratner and more recently participating in the NIDDK flagship effort in pelvic pain, the MAPP Research Network. Now, I have been especially honored to serve on the ICA board.

Shelley Kadron, ICA board member

More than 20 years ago, I called the ICA when I was in a tremendous amount of burning, searing pain. The ICA was incredibly helpful and provided information and resources. It was wonderful that the ICA was there to talk to me and help me through a rough time.

Ilka Graham, ICA board member

Throughout my eight-year journey with IC, I have found that my greatest resource has been the ICA. I was very fortunate when I found their support group early in my diagnosis. I was able to collaborate with other IC patients to find over the counter items that work for me as well as delicious recipes that made the transition to the IC diet easier. I have found that the resources given by the ICA have been priceless in my journey to recovery. In 2023, I was given the opportunity to join the board of directors for the ICA. I think seeing the hard work and dedication from the board made me realize that I'm not only grateful for what the ICA does, but also those involved in the ICA and what they stand for. I believe a large part of my healing has been thanks to the ICA and those patients in the ICA support group. They helped provide me with a holistic whole body health journey that I do not think I would have gotten otherwise.

Claudia King, former board chair

The ICA was the first place I turned after I was diagnosed with IC in 2005. I was confused, scared, and overwhelmed. My life had profoundly changed, and I was not ready for that to happen. Almost overnight, I was unable to work and unable to properly control my new symptoms. The ICA helped give me the support and education I so desperately needed at that time, and also helped me find an appropriate specialist for treatment. This 40th anniversary is a time to reflect on how many people the ICA has positively affected through education, lobbying efforts, awareness, and community. This organization is a necessity to the IC community and is absolutely irreplaceable.

Callie Krajcir, RD, ICA board vice chair

I did not discover the ICA until I already had relief. I was so upset that I didn't know about it earlier; I wish my doctors and other practitioners had referred me to the ICA because it is such a vault of knowledge, and it would have saved me a lot of time and procedures and medications that really weren't right for me and ended up prolonging my journey to getting relief.

I think we're really making a positive impact on the IC community—and helping patients advocate for themselves and feel empowered on their journey, because that is so important.

BREAKTHROUGHS: Four Decades of Progress

Rhonda Garrett, former ICA information specialist

One of the biggest original goals of the ICA was to secure funding for IC-specific research so that we could find better diagnostic tools and treatments. Unfortunately, doctors were still using the potassium sensitivity test as a diagnostic tool and stretching urethras as a treatment. It was all very barbaric. The ICA was absolutely responsible for getting those practices out of the healthcare protocol. We worked tirelessly to meet these challenges while also creating alliances with medical professionals who could implement changes for the better. We got involved with the AUA and took every possible opportunity to support research. It was exhausting, but we had seen the horrors of the past and could not fathom it continuing.

Heather Florio, Desert Harvest CEO

The ICA has been part of Desert Harvest's journey from day one, first as a personal journey and then as a professional journey that has continued to flourish and grow over the years. My aunt had IC and was looking for resources. She and my mother connected with Vicki Ratner and got a wealth of information that helped guide her and helped us discover the connection between IC and aloe vera. Vicki saw all those patients who had no resources and felt alone and misguided. ICA gave them direction.

Jill Peters-Gee, MD, ICA Medical Advisory Council member

Our understanding of IC has dramatically evolved. What we once believed to be solely a bladder disease has revealed itself to be a much more complex condition. The concept of central sensitization, and how we can address this clinically, is a real game changer. We can now have more personalized treatment plans, and hopefully help more individuals get the relief that they seek.

This shift in understanding has been pivotal in reshaping our approach to diagnosis and treatment. Thanks to the MAPP Network, we now recognize that there are different subtypes or phenotypes of IC and bladder pain syndrome.

The knowledge we have gained over the years, in large part due to the efforts of the ICA, has empowered both patients and healthcare providers to approach IC with a more holistic and personalized mindset. We have learned so much over the past 40 years!

David Klumpp, PhD, researcher and ICA board member

We have come far but still have far to go. Increasingly, the dark ages are behind us, where patients often struggled many years simply to get validation through a diagnosis. The findings of MAPP and other studies have begun to define clinical subgroups of IC patients and brain biomarkers associated with pelvic pain. And through the years of advocacy by the ICA and now the resources of the internet, IC patients are learning more about their own health, finding tools to promote their wellness, and finding support within a community. Despite these important advances, we still need to provide IC patients and their health management teams with new therapies that can only result from a continued commitment to research.

Naomi B. McCormick, Ph.D., clinical psychologist

The progress in research has been exponential and our understanding of IC/BPS is much better than when I was first treated. Many of the same treatments are used but in improved ways. All of this has given us more hope and enabled IC patients to have improved coping strategies. In addition, IC used to be an invisible orphan disease supposedly exclusive to women. Now, we know that both women and men can have IC and/or pelvic floor dysfunction, and people do not go undiagnosed or misdiagnosed as long as when I had been a young woman.

Raveen Syan, MD, ICA Medical Advisory Council member

Growing interest is developing in trying to characterize different phenotypes of IC/BPS so that treatment can be better individualized and targeted towards one's specific symptoms. Though we have a long way to go still, I am encouraged by the engagement of researchers (including myself!) in working towards improving patient outcomes.

Callie Krajcir, RD, ICA board vice chair

It's good to see that there are many research studies happening right now—the more the merrier when it comes to finding care for this condition, because everybody with IC deserves to get relief, and the ICA is helping us all get there.

THE IMPACT: ICA's 'Transformative Effects'

Jill Peters-Gee, MD, ICA Medical Advisory Council member

As someone who has spent nearly 40 years in the field of urology, I have witnessed firsthand the transformative effects of the ICA's work. I have seen patients who once felt isolated and hopeless find comfort and community through the resources provided by the ICA. I have also seen how the organization's advocacy has driven significant advancements in research, leading to new treatments that have improved the quality of life for so many.

Dan Vickery, former ICA board member

It's amazing what the ICA has done with the limited resources it has. The cliche is true—it punches way above its weight. The smallest dollars end up going a long way. It's amazing what gets done with the funds we have.

‘We Put IC on the Map’

An IC/BPS patient who had struggled to receive a diagnosis and treatment while still a student in medical school, Dr. Vicki Ratner, MD, founded ICA in 1984. Now retired and active in a wide range of civic activities in her California community, Dr. Ratner recently spoke with ICA Update *about her experiences and the organization’s impact in the decades that followed.*

We basically put IC on the map.

Up until 1985, IC/BPS was thought to represent the end stage of an irritable bladder [caused] by “unconscious hatred,” as it was described in *Campbell’s Urology*. That’s where we started—at a negative, not even at zero. From where we were then to now is just extraordinary, I think.

I found the answer I was looking for in the medical library. I was driven for two reasons—because no one should have to go through what I had to go through, and no one should have to live with the level of pain I lived through. I wanted help for these patients.

We started very small. I worked evenings and weekends because I was an orthopedic surgeon. It worked to my advantage to be on the West Coast because I could get up early and get some phone calls done before I had to leave for work.

The public awareness we gained early on was amazing. As for *Campbell’s Urology*, I wrote to the editor, and he took the chapter out for the 1986 version.

A ’Tremendous Amount of Support’

Over the years, we put together a fabulous comprehensive website, brochures, and fact sheets on many topics. We got IC/BPS on the official listing for Social Security disability. When we had enough money, we launched the pilot research program and were able to put out requests for applications for researchers, which was necessary for the kinds of information we were looking for in research—pain management, treatment modalities, and markers. Forty percent of the ones that got our stamp of approval went on to get NIH funding, which is extraordinary.

The most amazing thing was the tremendous amount of support from NIH. Senator Harry Reid (D-Nevada) was a key support for many years.

We attended the American Urological Association meeting every year. We eventually got a poster session, and then we got some courses on IC/BPS, which is quite remarkable. We also had an excellent Medical Advisory Board, which gave us a lot of credibility. These doctors were busy, and when we would call for help, they would put down what they were doing and speak to us.

Now, diagnosis and awareness are much better than they were 40 years ago. The epidemiology is much more clear, starting with the first study done in 1987 by Philip Held from the Urban Institute along with NIH. The quality of life was determined to be worth than that of patients with end stage renal disease on dialysis.

‘We’ll Be Able to Find the Answer’

We started as a nonprofit organization in 1984, and we’re still the only nonprofit [for IC/BPS] in the United States. I’m optimistic that we’re still here—a lot of organizations fold, and ICA survived COVID, which was not an easy task. We’ve got great leadership, a great Medical Advisory Council, a great Board of Directors, and a lot of programs that are very helpful that patients can count on for support. Working with fabulous people made a big difference.

There’s lots to be optimistic about, but it’s still frustrating that people live with terrible symptoms day to day. I’m really proud we got the disease on the map and we’ve made so much progress through epidemiology, a great medical advisory board and board of directors, the ability to get disability benefits, and a comprehensive website and a great, dedicated staff. I’m optimistic that through continued effort and funding, we’ll be able to find the answer.

The voice we have for government stakeholder awareness of this condition is one of the areas where the ICA has really outperformed. The FDA had an advisory committee meeting for IC/BPS treatments. People don't realize how substantial that is—to have one for this condition is really remarkable.

Jeffrey G. Proctor, MD, urologist and Medical Advisory Council member

When I first finished my residency in 1992, IC/BPS was considered a rare disease. Research has shown it to be a lot more prevalent, but to this day a lot of people have not heard of IC, and people wonder if they're the only one with it. It's very important that patients know that they're not in this alone—there are a lot of people with IC/BPS, and there's comfort in that. There's a tremendous amount of support.

Barb Zarnikow, former ICA board chair

One of the biggest gains I've seen is greater knowledge. People are finding the right kinds of doctors to go to —urologists or urogynecologists. They're also finding support from what things work for other people. So each new patient isn't starting all over with everything. People being diagnosed now have no idea that years ago we couldn't get a diagnosis. You'd go into a doctors office and you'd leave crying, feeling like no one believes you. Now we've encouraged people to have a voice. ICA is the voice for people with IC—and that lets you talk about it. I was recently at O'Hare—my flight was delayed, and a girl sitting next to me at a restaurant asked if I wanted to order food and share. I said I had dietary restrictions, and I found out that she had IC, too. If we don't talk about it, nobody knows.

Pradeep Tyagi, PhD, researcher and ICA Medical Advisory Council member

My PhD dissertation on intravesical drug delivery for the intractable disease of interstitial cystitis introduced me to a young association that had just celebrated its "sweet sixteen" birthday. Congratulations on navigating the twists and turns of politics, patient advocacy, research, and education on interstitial cystitis for 40 years. I am extremely proud of my association with ICA as I have progressed from being a graduate student to a professor engaged in translational research on interstitial cystitis by blending my expertise in pharmacology with radiology and proteomics.

Laura Santurri, PhD, MPH, CPH, aPHR, ICA Executive Director

For 40 years, the ICA has served as the premier national organization dedicated to the IC/BPS community in the United States. Its board, staff, and volunteers are responsible for ensuring federal research funding and national awareness of the condition, along with providing much-needed education and community for patients and the people who care for them, including healthcare providers. I view the organization's future brightly, knowing that this amazing group of individuals will continue to do all they can to support this community.

THE NEXT FOUR DECADES: Hope for the Future

Barb Zarnikow, former ICA board chair

People don't always see the progress because what they want is the endpoint. But we've gotten so much closer. We're finding ways to diagnose IC so it's no longer a diagnosis by exclusion. Once that happens, we're going to have access to so many more treatments that could be used off-label. Someday they'll crack this whole thing.

Teri Cooper, volunteer advocate

They catch IC/BPS so much more quickly, and when they do, it's easier to treat. That's why some of the alternative treatments work well. It goes back to how educated doctors are so they can diagnose it. I know when I was sick, I went from doctor to doctor—they thought I was crazy. Now if you catch it faster and deal with it from the beginning, there aren't as many bad consequences.

Naomi B. McCormick, Ph.D., clinical psychologist

I think that IC will become a manageable chronic condition and patients will have a higher quality of life than previous generations like my own. At the same time, I do not believe that there will be a complete "cure" for this condition or what may be several interconnected medical conditions causing painful bladder symptoms and urgency. Patients need to think holistically. It is not just about finding the right doctor or treatment; it is about building a whole life despite chronic medical symptoms. Life building requires purpose and self-care. Regular exercise, hobbies, socializing, devoting oneself to a cause bigger than oneself, engagement with family and friends, creative self-expression, faith or spirituality, appreciating nature—all of this is as important to managing IC as medical treatments. We are not our disease; we are bigger than our disease!

Amber Carter-Frauenhofer, ICA board chair

It's amazing watching the ICA advocate for patients, educate healthcare providers, and work with Congress to raise awareness and funding. Knowing the ICA is fighting for patients like me provides such an inner peace. Thanks to the ICA, IC/BPS awareness has come a long way, and I am filled with positive hope for what the future will bring!

Rhonda Garrett, ICA information specialist

I still have IC. I have periods of time with little disruption to my daily life. During those times, I get energized and feel like I've turned a corner for good. However, I also have periods of time when the symptoms return with a vengeance, and I feel just as vulnerable as any newly diagnosed person might feel. There's a constant fear of "I don't want to go back! I don't want to repeat the experiences of the past!"

I think all IC patients learn to be strong. They must because there is little other choice. My hope for the future is for that ambiguity to disappear, making the complexities of IC come into clear focus for everyone involved—patients, their loved ones, medical professionals, and researchers.

Claudia King, former board chair

My hope is for an accurate diagnostic tool and a cure for IC/BPS. I hope that research dollars increase and match that of other diseases. I hope for more and more healthcare providers to properly understand IC/BPS and learn how to provide appropriate and thoughtful care for patients.

Dan Vickery, former ICA board member

We run clinical trials, and you see that the patient population has changed. They're getting healthier. Patients are able to manage the condition better, determined by the framework that the ICA has helped support over all these years. They've gone a good job of taking the diagnosed population and making sure they're getting the best treatments that are currently available.

I've always tried to focus on what we can do. If we can get one new treatment approved, that will change the dynamic for everybody. A rising tide will lift all boats, and that will make a difference in the lives of these patients.

Linda Salin, former ICA staff member and volunteer

My first experience with the ICA was over 30 years ago, and I was lucky to get a diagnosis right away from a young urologist. Now almost every lay person knows someone with IC/BPS, and the vast majority of doctors are at least familiar with the name and have a degree of empathy as well as knowledge about the condition.

I have seen the amount of research explode over the last few years. While we have not found a cure, we have found a lot of help via pain management, devices for pain and urinary frequency, and pelvic muscle physical therapy, to name a few. There are lots of medications and treatments for IC/BPS in current clinical trials.

I believe the ICA is responsible for the recognition and the vast amount of knowledge in the patient population and medical field. If it were not for the ICA, this disease would still be hidden and not believed in. We have our founder, Dr. Vicki Ratner, and our leadership, volunteers, and staff throughout the last 40 years to thank.

Dr. Theo Theoharides' message last year at the Clearwater conference was to not lose hope. We have come a long way and have every reason to be hopeful and continue our journey to good health with the ICA supporting us every step of the way.

FOUR DECADES OF SUPPORT, ADVOCA

1984

ICA's **articles of incorporation** signed.

1985

ICA Founder Dr. Vicki Ratner appears on ***Good Morning America***, generating thousands of phone calls and letters.

1986

ICA kicks off **funding efforts** for research.

1987

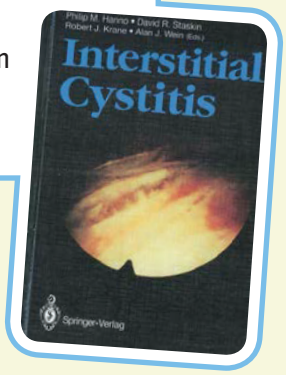
First NIH workshop on IC is held by NIDDK.
First epidemiology study of IC begins, revealing how frequently the condition is misdiagnosed and that the number of U.S. IC patients was ten times higher than believed.
Newspaper advice columnist **Ann Landers** refers people to ICA for answers.

1988

NIH develops a **research definition of IC**—another step towards widescale recognition of the condition.

1990

Congress earmarks $2.5 million specifically for IC research for the first time.
Epidemiology of Interstitial Cystitis, the first medical publication focusing specifically on IC, is published.



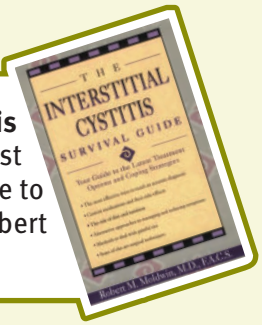
1992

NIH funding for IC doubles to $4 million.

ACY, AND HOPE FOR IC/BPS PATIENTS

ICA launches **website**.

ICA enters first of two five-year cooperative funding agreements with the **Centers for Disease Control and Prevention (CDC)**. The **AUA** holds its first plenary session on IC.



The Interstitial Cystitis Survival Guide, the first patient-centered guide to IC, is published by Robert Moldwin, MD, FACS.

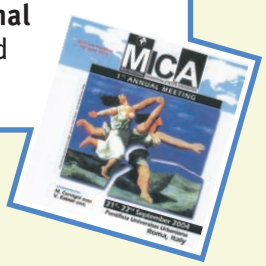
1995 1997 2000 2002 2003 2004 2005 2007

The Fishbein Family IC Research Foundation becomes the first **privately funded IC research foundation**, administered by ICA.

ICA Update becomes a four-color magazine and is sent to physicians' offices for the first time.

The Social Security Administration rules that IC is a condition that can be a basis for **federal disability benefits**.

The Multinational ICA's **first international meeting** is held in Rome.



FOUR DECADES OF SUPPORT, ADVOCA

2008

NIH launches the Multi- Disciplinary Approach to the Study of Chronic Pelvic Pain **(MAPP)** research network to study the relationship of IC with other overlapping chronic conditions. Ratner **retires** as president and chief medical officer of ICA.

2009

The RAND Interstitial Cystitis Epidemiology (RICE) study reveals **significantly higher numbers of people suffering from IC than previously thought**—as many as 8 million women in the U.S. alone.

2011

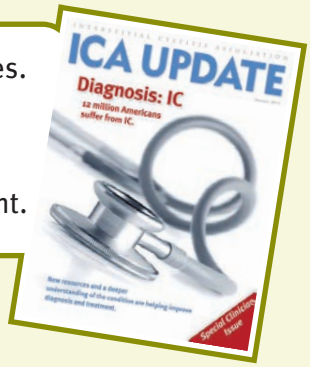
AUA releases the **first clinical guidelines for treatment of IC**, providing a clear roadmap for physicians unfamiliar with the condition.

2012

ICA runs two-page spread on IC in ***USA Today***.

2013

ICA's **Online Support Community** launches. ***ICA Update*** is distributed to more than 100,000 medical professionals, many of them primary care practitioners, to help increase awareness of IC and its treatment.



2014

National Pain Strategy is released, including recommendations from ICA.

2015

The **Social Security Administration** (SSA) refines its 2002 ruling establishing IC as a medically determinable impairment (MDI) with less ambiguous language. **ICA Pilot Research Program** funds its 100th IC research project.

2016

More than 1,000 **billboards** highlighting IC awareness appear across the nation. ICA releases an **online continuing medical education program** to help physicians identify and manage the symptoms of IC.

ACY, AND HOPE FOR IC/BPS PATIENTS

Researchers at Beaumont Hospital collaborate with ICA on **developing a new biomarker** for IC diagnosis.
ICA staff and patients testify at FDA public hearing on **clinical trial criteria** for IC patients.

Walks for an IC Cure become local, with events in California, North Carolina, Georgia, and Arizona.
ICA urges HHS, CDC to **revise opioid guidelines** to address needs of chronic pain patients.

AUA releases **revised IC/BPS guideline**, emphasizing individualized treatment and a concurrent, multimodal approach to care.
ICA collaborates with Black Health Matters, Inspire, Boston Children's Hospital on CDC survey to identify **underrepresented IC/BPS populations**.

ICA earns **four-star charity rating** from Charity Navigator.
ICA becomes **led and run by patients**, for patients!

2017 **2018** **2019** **2020** **2022** **2023** **2024**

ICA hosts inaugural ***Walk for an IC Cure*** in San Diego, California.

COVID-19 pandemic leads to virtual advocacy, fundraising and education events; ***Virtual Walk for an IC Cure*** participants raise more than $50,000.
Studies suggest an association between the use of the only FDA-approved oral medication for IC/BPS, **pentosan polysulfate sodium** (Elmiron), and retinal abnormalities (called "pigmentary maculopathy").
ICA survey of 1,500 patients finds pelvic pain the most common symptom, diet and stress the greatest symptom triggers.

ICA reconstitutes **Medical Advisory Council**.
International Society for the Study of Interstitial Cystitis/Bladder Pain Syndrome (**ESSIC**) reconvenes after COVID, recognizes patient advocacy groups including ICA.
IC/BPS proclamations made by governments in Texas, Colorado, Illinois and cities nationwide.

‘A Glaring Hole’

Patients advocate for better research into the connections between IC/BPS and hormones.

The role hormones play in IC/BPS symptoms for many patients remains one of the unresolved questions around the condition, one for which only limited research has been done to date. Avery Singer, Holly Goodwin, and Abi Agoglia are three IC/BPS patients who have struggled with the condition since childhood. They spoke with *ICA Update* about their experiences, the real-world impact of the lack of research, and what greater insights into the role of hormones could do for treatment.

How do hormones affect your IC/BPS?

Goodwin: Hormones are an extreme component to my IC/BPS. I flare during ovulation and a week before and after my period. It feels like I was being stabbed, with nerve pain going straight down to my urethra. It wasn’t originating in the bladder, but ending in my urethra.

Agoglia: It was consistent earlier in life—a flare four to five days before my period with 14 days duration. It was one good week a month and the rest was a total loss. Moving towards menopause, I’m finding I’m getting these ovulatory flares.

The other reason I think there’s a hormonal component for me is that I got huge relief from a hormonal IUD which suppressed my hormones.

Singer: I was used to having these extremely painful periods—more painful than most other people. Oddly enough before I had my endometriosis treated, my period pain would alleviate my IC/BPS pain. I didn't understand why—is your brain distracted by another pain generator? But I also have intense back pain, and that doesn't distract me from my IC/BPS pain.

How have you talked with your healthcare providers about these experiences?

Goodwin: I've always mentioned the pattern. The most a doctor did was put me on continuous birth control, and I would come back and say I'm on it and it's not working—that I was still having this pain every four weeks, circling on my birth control pills where the pain is, and that I was flaring on the dot. The doctor said it shouldn't be cycling like that, and I would have to go off birth control to test my hormones.

Singer: The urologist never wants to prescribe any form of hormones—they want to hand it off to a gynecologist. When I see the gynecologist, they don't work with IC/BPS, so I go back and forth between these two silos of medical knowledge. Maybe a urogynecologist might be more comfortable with this, but even the one I saw never had anything helpful to say about it.

Agoglia: Lots of us have experienced roadblocks with doctors. There's a weird lack of curiosity when you bring up these kinds of menstrual symptoms. One urogynecologist once told me that it doesn't make any sense—I don't know what to do with that.

I never had anyone offer to test my hormones, even though I had other menstrual symptoms. I think some are just squeamish about having anything to do with the menstrual cycle.

Singer: Treatment for ovarian health is poor, and the organs are so close together it can become very challenging to identify your pain generator. This topic is enshrouded in mystery, and that's why we're having this conversation. Research needs to be done.

What's the impact of the lack of research?

Agoglia: The American Urological Association guideline [for IC/BPS] hasn't really focused on hormones—it's more about bladder-centric treatments. It's frustrating to find a place for any clinician to start investigating hormones and acting on it if there's no guidance available.

The fact that there's a hormonal component is glaringly obvious when you talk to more than four or five people. In the absence of research, patients are doing their own—we see people telling patients they have to get on birth control to treat their symptoms, while others say you have to get off of it. None of this has a medical source, and none of it is medically valid.

Patients are trying to find an actionable solution. If we can't give them one, they will go to trial and error—which can be pretty damaging.

Singer: There are also predatory people who try to make money selling products to control your hormones. They're chasing desperate patients and marketing useless products that have not been studied and have no medical basis to be used for IC/BPS.

What's the impact of the lack of research?

Singer: Anecdotally, we know it's a big issue for many IC/BPS patients. We often vent about it to each other because our doctors have no answers. We don't have tests to know where the pain is coming from. We don't have good diagnostic methods to narrow down pain generators or the relationships to our menstrual cycles.

The goal is research to provide better and more effective treatments for patients. The female body is under-researched; men's bodies are more medically understood and historically have been a priority medically. What we're asking for is to be an equal priority medically, because we're half of the population, and the IC/BPS patient population skews female.

Up until the 1990s, women didn't have to be included in medical studies. We're making progress, as much as we can.

Agoglia: There have been some studies on the effects of the menstrual cycle or estrogen/progesterone/testosterone on IC/BPS symptoms (see box, pg. 22). There's not much there, but there are some interesting threads that just haven't been followed up on.

It drives me bonkers that we have a really easy way to identify women's menstrual hormones. You can mark it on a calendar. It's a great built-in system that's noninvasive.

There are also tons of FDA-approved drugs that impact hormones—things general practitioners are comfortable with and

can prescribe. The lack of information is a glaring hole: What is the spectrum of reactions to drugs that affect hormones? We know birth control can help some people and for others it does nothing. The same for perimenopause and endometriosis—I'm most interested in those basic first questions.

What could happen to IC/BPS treatment if the role of hormones was better understood?

Agoglia: A good point of intervention is more with general practitioners and internists. They are familiar with drugs that impact hormones, and there are all these minimally invasive treatment options that a general practitioner can try beyond physical therapy referrals.

Singer: We think of IC/BPS has having subtypes, but we don't even have a hormonal subtype. If only doctors were able to evaluate patients and say you fall within a subset of a hormonal subtype—but within that, you're in your 40s and perimenopausal, so we can perform a test to determine what to do given your unique hormonal profile given your age and biomarkers and tailor a treatment for you.

SELECTED RESEARCH

Researchers have explored the relationships between hormones, the menstrual cycle, and IC/BPS since the 1990s. Below are key studies and findings, although many involve small sample sizes.

Menstrual cycle affects bladder pain sensation in subjects with interstitial cystitis (2005). Study of seven IC patients and eight controls found that subjects with IC had higher pain scores and frequency than controls throughout the entire menstrual cycle. Pain and frequency were highest during perimenstrual period and evoked bladder pain from bladder filling was higher during the luteal phase than the follicular phase.

Hormonal manipulation in women with chronic, cyclic irritable bladder symptoms and pelvic pain (2002). Study of 10 IC and 15 IC/endometriosis patients found symptom improvement in eight of nine women treated with leuprelide and five of six women treated with birth control; no differences between patients with or without endometriosis.

The association of dysmenorrhea with noncyclic pelvic pain accounting for psychological factors (2013). Survey of 1,012 participants with pelvic pain found dysmenorrhea (menstrual pain) was associated with more severe noncyclic pelvic pain.

Hormonal contraception and pelvic floor function: a systematic review (2015). A meta-analysis of 13 studies found that the use of hormonal birth control was associated with IC, but timing and causal relationship could not be established.

Sexuality and reproductive risk factors for interstitial cystitis/painful bladder syndrome in women (2011). Case-control study with 312 participants found that IC/BPS patients were slightly more likely to have used birth control than controls (88% vs. 82%).

Interstitial cystitis is associated with vulvodynia and sexual dysfunction–a case-control study (2011). Case-control study with 47 IC/BPS participants found past or current hormonal birth control was associated with IC/BPS.

Circulating sex steroids and bladder pain sensitivity in dysmenorrhea (2021). Study involving questionnaires, noninvasive bladder capacity, pain, and urinary hormone testing found that patients with dysmenorrhea and bladder sensitivity had higher estradiol concentrations than controls during the luteal phase, BPS patients had higher concentrations of sex hormone-binding globulin than controls, and that there were no differences in prior hormonal contraceptive use between groups.

Effect of local estrogen therapy (LET) on urinary and sexual symptoms in premenopausal women with interstitial cystitis/bladder pain syndrome (2015). Study of 34 IC/BPS patients treated with estriol cream for 12 weeks found that treatment improved symptoms and sexual functioning.

Bladder mast cell expression of high affinity oestrogen receptors in patients with interstitial cystitis (1995). Study of six IC patients and four controls with bladder biopsies and immunohistochemistry (IHC) found that bladder mast cells expressed the estrogen receptor, and staining for the estrogen receptor was higher in samples from IC patients compared to controls.

Estrogen and progesterone receptors in patients with bladder pain syndrome (2013). Study of 15 BPS patients and 10 controls with bladder biopsies and IHC found that staining for estrogen and progesterone receptors was not different between BPS patients and controls.

Intragranular activation of bladder mast cells and their association with nerve processes in interstitial cystitis (1996). Study of 26 IC patients and six controls with bladder biopsies and electron microscopy found that most mast cells express the progesterone receptor, but there was no difference between IC patients and controls in terms of progesterone receptor staining.

Sources: PubMed, Abi Agoglia

Online IC Resources

- **ICA Website:** ichelp.org
- **ICA Email:** icamail@ichelp.org
- **The IC Plate™:** ichelp.org/the-ic-plate/
- **Donor Resources:** ichelp.org/donor-benefits-and-how-donations-are-used/
- **ICA Online Support Community:** ichelp.org/online-support-groups/
- **ICA Store:** ichelp.org/shop
- **Facebook Page:** facebook.com/InterstitialCystitisAssociation
- **Twitter:** twitter.com/ichelp
- **YouTube:** youtube.com/user/ICHelp
- **LinkedIn:** linkedin.com/company/interstitial-cystitis-association
- **Pinterest:** pinterest.com/ichelp
- **Instagram:** instagram.com/icahelp/
- **ICA Navigating IC/BPS webinars:** ichelp.org/navigatingicbps
- **ICA eNews:** ichelp.org/ica-enews/
- **ICA Webinars:** ichelp.org/videos-webinars/
- **Get the Facts:** ichelp.org/newly-diagnosed-toolkit/
- **Find a Healthcare Provider:** ichelp.org/healthcare-provider-registry
- **Find an IC Support Group:** ichelp.org/us-support-groups/

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- **Provide superior healthcare products at a fair price**
- **Passion to provide high quality products and value**
- **Strive for continuous improvement and growth**
- **Uncompromising integrity and honesty in all communications**

OUR LEADERSHIP

Each member of the leadership team has extensive experience developing products that meet consumer needs and bringing them to market. A common experience they share is that they were all executives at Johnson & Johnson.

Learn more at dsehealthcare.com

Or visit prelief.com for more information

Join ICA's Angel Society — Become a Monthly Donor

Be an ICA Angel with your convenient, tax-deductible monthly donation. Your recurring contribution as small as $10 will give you online access to ALL the back issues of the award-winning *ICA Update* and will help sustain ongoing education, awareness, research, and advocacy for those suffering with IC. Join ICA's Angel Society online today! Your credit card will be charged the amount you designate on the same date each month and can be changed or cancelled at any time.

Sign up now at ichelp.org/recurringdonation or contact ICA at 720-515-1411.

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40 YEARS, BY THE NUMBERS

14

Number of physicians who told ICA Founder Vicki Ratner, MD, that her IC pain was 'all in her head'

6 Million

Estimated audience of Dr. Ratner's first *Good Morning America* appearance on ABC

$30,000

Cost of the first 1987 epidemiology study of IC supported by ICA

170+

Number of research papers published about IC/BPS since ICA's founding

25,000+

Members of ICA's Online Support Community

$2,506

Average annual cost of IC/BPS care, according to 2022 ICA survey

9.8 Million

Number of steps logged by patients and advocates during 2020's virtual *Walk for an IC Cure* events

$1.7 Billion

estimated annual impact of IC in medical costs and lost wages

2012

Year in which physical therapy was formally proven to be an effective IC/BPS treatment

Interstitial Cystitis Association

388 S. Main Street, Suite 440-#157
Akron, OH 44311

ICA gratefully acknowledges these generous partners for their commitment to ICA, and support of our efforts to conquer IC and change lives.

Want your organization listed here? Learn how at ichelp.org/get-involved/for-corporate-partners

What Is 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/BPS. ICA advocates for research dedicated to discovery of a cure and better treatments, raises awareness, and serves as a central hub for the healthcare providers, researchers, and millions of patients who suffer with IC/BPS.

Are You on the List?

Sign up for the ICA email list to receive updates from ICA. Go to ichelp.org to register!

Conquering IC/BPS. Changing Lives.