INTERSTITIAL CYSTITIS ASSOCIATION

ICA UPDATE

Spring 2023

The TOUGHEST JOB You'll Ever Love

Advice from parents with IC/BPS.

2022 ICA Annual Report • Avoiding 'Medical Gaslighting'

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Please consider supporting ICA as an Advocate ($100 or more) today! You'll directly help yourself and those who need our help most: the IC/BPS community of patients, doctors, and researchers. You'll also receive access to valuable and informative resources that will keep you abreast of the latest IC research, news, and ICA announcements.

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

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ICA UPDATE
Interstitial Cystitis Association

Conquering IC. Changing Lives.
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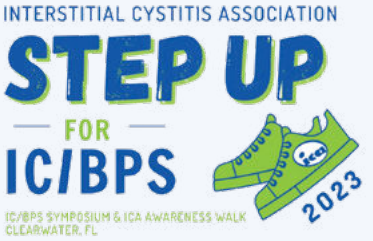
ICA News

ICA Holds IC/BPS Awareness Walk and Symposium in Florida



ICA partnered with Nova Southeastern University's Institute of Neuro-Immune Medicine, Dr. Kiran C. Patel College of Osteopathic Medicine (KPCOM) to host an IC/BPS Symposium and Step Up for IC/BPS Awareness Walk on Saturday, March 11, 2023 in Clearwater, Florida.

This unique day-long event took place at Nova Southeastern University in Clearwater, with the daylong symposium offered both in person and virtually. It was followed by the *Step Up for IC/BPS Awareness Walk*. Topics included Diet & IC/BPS, Getting to Know You and Your IC/BPS, Comorbidities and Neuroinflammation, and more. Healthcare providers had the opportunity to receive a certificate of attendance from Nova Southeastern University which could be used for continuing education credit.

Speakers included: **Robert Moldwin, MD, Robert J. Evans, MD, Kristene Whitmore, MD, Theoharis Theoharides, MS, MPhil, PhD, MD, FAAAAI, Kenneth Johnson, DO, FACOOG, Nancy Klimas, MD,** and **Amber Carter** of the ICA Board of Directors.

Together, the events helped ICA raise nearly $8,000 to allow ICA to continue providing much needed educational events to the IC/BPS community. Thank you to our top fundraisers, **Amber Carter, Linda Salin,** and **Barbara Zarnikow**. We also are deeply appreciative of our corporate sponsors: **Algonot** (Presenting Sponsor), **Ironwood** (Platinum Sponsor), **West Coast Mint** (Gold Sponsor), and **Prelief** and **Carzato** (Silver Sponsors).

It's not too late to support ICA educational events! Visit bit.ly/ICA23Walk to learn more.

ICA Advocates on Capitol Hill

ICA continues to be the voice for people living with IC/BPS on Capitol Hill! On Monday, March 6, ICA Executive Director **Lee Lowery** and ICA's Washington representative met with staff at eight Congressional Offices, including **Sen. Brian Schatz (D-HI), Sen. Tim Kaine (D-VA), Sen. John Boozman (R-AR), Sen. Jack Reed (D-RI), Rep. Andy Harris (R-MD), Rep. Mario Diaz-Balart (R-FL), Rep. Steve Womack (R-AR),** and **Rep. Robert Aderholt (R-AL)**.

But we can't do it alone! Patient stories are vital to making IC/BPS real to lawmakers and helping them understand the impact of the condition (see p. 22 for one example). To learn more about ways to educate your representatives about IC/BPS, visit ichelp.org/get-involved/advocate/.

Two IC/BPS Research Studies Seeking Patients

Two separate research studies are seeking patients to evaluate investigational medications—meaning those which are not currently approved for clinical use—for the potential treatment of IC/BPS in women.

OAG1050 study

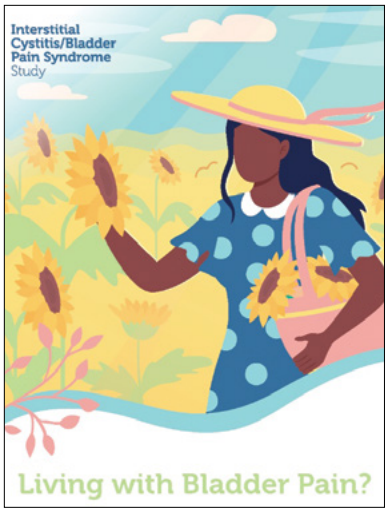
The OAG1050 study is testing an investigational medication that is designed to help alleviate the symptoms of interstitial cystitis (IC) and bladder pain syndrome (BPS). The investigational medication is a tablet taken once daily before bed.

You may be able to join this study if you:

- Are a female between 18 and 70 years of age
- Have been diagnosed with interstitial cystitis or bladder pain syndrome or have been experiencing bladder pain, pressure, or discomfort accompanied by a frequent need for urination that is not due to other causes (e.g., infection) and has persisted for at least 6 months
- Are willing to travel to the clinic up to 9 times during an 8-week study treatment period
- Are willing to use a computer or cell phone (can be your personal device) to monitor and record information daily about your pattern of pain and urination for the duration of the study

If you qualify, you will receive — at no cost — access to the investigational medication, careful evaluation and close monitoring of your condition, and the opportunity to help advance the treatment of interstitial cystitis and bladder pain syndrome. Reimbursement may be available for study-related time and travel expenses.

To learn more, visit bit.ly/OAG1050-ICA.



Interstitial Cystitis/Bladder Pain Syndrome Study

This IC/BPS study also involves an investigational medication to alleviate symptoms, this one a liquid solution administered as an injection into the bladder.

Qualifying patients will receive one treatment of either the investigational drug or placebo.

This portion of the study will last up to 28 weeks and will consist of up to nine visits to the study center, including two phone visits. Participants will also be asked to complete an electronic study diary to keep track of urination and bladder pain.

After at least 12 weeks following the first treatment, patients may choose to receive a second treatment. This second treatment will be the investigational drug. Depending on if and when they request a second treatment, total participation in the study will last between approximately 26 to 46 weeks with a total of up to 13 visits.

You may be able to join this study if you:

- Are a female between 18 and 75 years old
- Have a confirmed diagnosis of interstitial cystitis/bladder pain syndrome

To learn more, visit ic-bpsstudy.com.

IC/BPS Expert Presentations Available to All

Thanks to generous donors like you, the ICA is able to offer "free" educational programs bringing IC/BPS healthcare experts and researchers to our community.

The most recent set of programming, which coincided with IC Awareness Month, focuses on awareness, advocacy, and education:

Awareness: ICA Board members living with IC/BPS— **Tacha Kasper, Claudia King,** and **Dr. Laura Santurri**— share their stories of hope and how they use their professional and personal experiences to raise awareness and bring hope to the IC/BPS community.

Advocacy: ICA Board members, staff, and volunteers demonstrate how they meet with members of Congress to discuss much needed research and awareness funding for the IC/BPS community.

Education: Programming available on demand, any time, includes *IC/BPS and the Pelvic Floor Connection* by **Dr. Nicole Cozean, PT, DPT, WCS**; *Expert Q&A Session with the IC/BPS Patient Community* by **Robert Moldwin, MD, FACS**; *Handling the Emotional and Mental Impact of IC/BPS* by **Tacha Kasper, MA, LMFT**; *Intimacy and IC/BPS* by **Alexandra Milspaw, PhD, MED**; *Understanding Healthcare Coverage* by **Melissa Fotinos, MS, CPC, CPMA**; and *CBD Preclinical Study* by **Dr. Reza Sharif**.

View these presentations on demand at ichelp.org/ica-2022-fall-event-expert-interviews/. And help keep our community informed and inspired by donating today. With your help, the ICA can continue to reach the IC/BPS community with important awareness, research, and educational programs as we look forward to new offerings in the coming months. Thank you!

Join the ICA Guardian Society

Join the members of the ICA Guardian Society, a group committed to supporting the ICA through a very special and important form of financial support. These donors named the ICA as a beneficiary of a planned gift. Such gifts might include a bequest or charitable income gifts, such as charitable gift annuities, charitable remainder unitrusts, charitable remainder annuity trusts, or gifts of life insurance. Ask an attorney or estate planner about your options.

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ICA Welcomes New Leadership

Four new members join the Board of Directors.

The ICA Board of Directors has new leadership and four new members. At the beginning of FY 2023, **Laura Santurri, PhD, MPH, CPH** moved into the position of ICA Board Chair, and **Claudia King** accepted the position of ICA Vice Chair.

ICA also welcomed four new members to its Board of Directors:

Sarah Cojocaru

With over 20 years of experience in the corporate and small business space, Sarah Cojocaru is an executive leader, serving as the vice president of automotive operations for Carzato LLC, an innovative digital commerce provider in the automotive technology sector. While focusing on growing her company's operational excellence, Cojocaru is supported by her loving husband who works in the medical field and their twin children, a son and daughter. Cojocaru has pushed for patient awareness for many years leading the Southeast Michigan Interstitial Cystitis chapter from 2012 to 2015. With her desire to help others, Cojocaru promoted awareness of the group and provided support to over 60 members in the Southeast Michigan area.

Janelle Faba

Janelle Faba is a technology professional who has worked in the Financial Technology industry for 20 years. She has held various senior management roles within the industry and is currently a VP in Information Security for a Fortune 500 FinTech organization. She holds many professional certifications, including the Project Management Professional and Certified in Risk and Information Systems Control, and she has a Master of Science in Information Systems Management from ASU. Faba resides in Arizona with her husband. Together they have six children; two adult children and four living at home.

Faba was diagnosed with IC/BPS in 2001, and through her work with the board she hopes to promote awareness of the condition in the medical and general community and to help all patients to find hope and relief.

Shelley Kardon

Kardon was diagnosed with IC/BPS more than 20 years ago and likes to say that she is an "IC survivor," since she is pain free today. She researched and educated herself about IC/BPS and worked with physicians, physical therapists, compounding pharmacies, and a pharmaceutical company to resolve her IC pain. Throughout this journey, she learned how to navigate a complex health issue. Kardon works in the fundraising office of a Philadelphia private university. She holds a BS in Human Behavior and Development and Education from Drexel University, an MA in Liberal Arts from the University of Pennsylvania, and an MS in Library Science from Drexel University. Kardon is an avid reader and enjoys sewing and making quilts. She lives in Philadelphia, PA and Brigantine, NJ with her husband Sean.

David Klumpp, PhD

Dr. Klumpp received a Ph.D. in biochemistry, molecular biology and cell biology from Northwestern University in 1994, studying retinal neuron physiology. After postdoctoral studies in HPV pathogenesis and epithelial biology at Northwestern's Feinberg School of Medicine, he joined the Department of Urology in 1998. He is a Professor of Urology and Microbiology-Immunology in the Feinberg School of Medicine and the Anthony J. Schaeffer MD Professor of Urology.

We would also like to thank **Dr. Michael Hsieh** and **Michael "Jay" Moss** for their service over the past few years, as their tenure on the Board ended this year.

The ICA Board of Directors includes people with interstitial cystitis/bladder pain syndrome (IC/BPS), family members, physicians, and professionals. The ICA Board guides strategic planning and organizational direction. Board members offer support for and spur interest in programs and services, and provide fiduciary oversight of organizational activities. This group of volunteers dedicates their time, expertise, and enthusiasm to ensuring ICA mission fulfillment.

Learn more about the board at ichelp.org/about/board-of-directors/.

The TOUGHEST JOB You'll Ever Love

Perfect parents don't exist, but real ones do —including those with IC/BPS.

By Mark Toner

Two years into a diagnosis with IC/BPS, Callie Dixon says that she's learned that "pain turns me into the mean mom at Walmart."

"You know who I'm talking about," Dixon wrote in a blog post on the healthcare site The Mighty. "Don't pretend you've never judged her."

Perfect parents don't exist. It's often repeated, but much harder to internalize, particularly when living with a chronic pain condition like IC/BPS. In many cases, being a parent means many things. Guilt. Presence. Uncertainty. Patience. Joy. Or, in the moment, as one parent puts it, "parenting from bed."

More than 50 parents with IC/BPS shared their thoughts, frustrations, and strategies for coping with *ICA Update*. "My biggest challenge was moving through the day while hiding my pain," one says.

More than anything, the parents who responded to the *ICA Update* survey describe a challenging balancing act, one made better by recognizing the importance of what they are doing. "My strong desire to be the best mother possible enabled me to do what I had to do to keep going," one says. "But during a flare this was very, very hard."

Parenting With Chronic Illness: A Common Challenge

Parents with a chronic health condition are more common than you might think. It's believed that 4 to 12 percent of people grew up in a household where a parent has a chronic illness—that's between 13 and 39 million people in the U.S. alone.

Research on the impact on these children's lives has been mixed—some studies have suggested silver linings in terms of strengthened interpersonal relationships and increased maturity, while others point to an increased risk of reduced family functioning and social-emotional and behavioral problems. A 2021 study published in *Frontiers of Psychology* found a significant connection between parental chronic illness and "internalizing symptoms"—anxiety, depression, sleep issues, and withdrawal—particularly for girls. "The study demonstrates the importance of targeting the entire family in chronic illness care," the authors state.

'PUSHING THROUGH THE PAIN'

The overarching goal of many parents living with IC/BPS, as one puts it, is to "try to push through the pain to be there for them in all the ways they need me."

"It's hard to keep up with my preschooler and toddler when it hurts to move," another says. "They don't understand that I don't feel good, and I find myself cranky when I'm in pain."

The unpredictability of IC/BPS symptoms was cited by many as a particular challenge. As one grandparent says, "not knowing how you're going to feel when you wake up in the morning—if I'm going to be able to attend my grandson's T-ball game."

Activities outside of the home prove especially difficult. "Running to the bathroom when out alone with him is a challenge," one parent says of her two-year-old son. "Privacy is also an issue, as I need to wear pads most weeks and he's curious."

Another parent recalls going with her child on a field trip to see the Statue of Liberty, only to have their time cut short because of a long line at a restroom. "I look back on many family events and vacations, and one of the first things that comes to mind is how bad I felt," another parent says. "IC even influences my memories."

Others talk about the challenges of managing their medical treatments as parents, which include scheduled appointments for procedures like instillations as well as time to recover at home. "Making sure it was on a day that I could arrange for someone to pick up my children from school was the biggest problem," one says.

But above all, parents with IC/BPS stressed how hard it is to be present in the day-to-day moments that make up a childhood. "Having the mindset to have fun without thinking about my flare-up or pain," one says. "Missing out on great moments because I'm feeling awful. Sometimes I let it make me pessimistic and I start complaining and my children hear. I'm afraid they internalize my complaining and the pain I'm in."

"I PUT MYSELF IN THEIR SHOES."

Parents who responded to the *ICA Update* survey say that what's helped them the most as parents is to think through what works for their children—and for themselves.

"I put myself in their shoes," one parent says. "I didn't want their core memories of their mom being negative and traumatic."

Among the strategies parents suggest:

BE HONEST. Parents discussed the challenges of knowing what to say to their children about IC/BPS—but almost all believe it's important to say something. "Kids do not like watching the adults they rely upon look helpless, but we cannot hide it from them," one parent says. "Give kids age-appropriate information, or they will make it up in their heads," another cautions. (See the story on the right for more.)

Even if parents decide to keep the details from their children, a serious flare may require a direct conversation. Says the parent of an 8 and 10 year old who had to go to the hospital for pelvic floor spasms, "We talked about my muscles getting tight and my bladder not feeling good. We mentioned how medical discoveries were being made constantly and we would find a way to ease my pain."

Along with letting children know about the condition, many parents say it's also important to be honest about the daily ups and downs of living with IC/BPS. "It's okay to say 'I need help' or 'I'm going to go lay down, come get me if you need me,'" one parent says. "Being part of a family means you help one another, and I believe in that and also not masking when I need help, unlike my parents' generation. Pushing through pain is not a positive experience and should not be masked as such." Another adds, "Don't mask the pain out of shame or guilt—pain is painful, and it's okay for your family to see that."

CONTROL WHAT YOU CAN—AND RECOGNIZE WHAT YOU CAN'T. "I try to 'be sick' while they are at school," one parent says. "I wash up or shower just before they came home so it doesn't look like I was in pajamas and in bed all day. Other times I am honest with them and tell them that I am in pain. I try to balance how often they see me sick and how often they think I feel well." Another adds, "if there's something I can't do or eat, then I re-direct and say well, how about this instead?"

"We will do the urgent things and the rest will have to wait," one parent says. "Be as present with your kids as you can possibly be, and let them bring you happiness," another adds.

Talking About IC/BPS With Children of All Ages

One parent with IC/BPS had a one-word response about how to talk about the condition with their children: "Truth."

"It's a hard thing to hide," another adds.

However, parents responding to the *ICA Update* survey stressed the importance of discussing living with IC/BPS in age-appropriate ways. As one parent put it, "I really didn't talk about my condition when they were young. My condition was my way of life, and I didn't burden them with it. When they began high school, they started asking questions when we socialized with relatives and friends and they saw what I ate and drank. I addressed their concerns after I stopped taking Elmiron and started having more flares that required frequent trips to my urologist. And at that time, I made sure they understood what IC/BPS was all about."

Examples of language parents with IC/BPS use at different ages:

2 and 3 year olds: "It's very hard to explain IC/BPS to young children, but my husband and I explained Mommy has pain in her belly and she needs to rest so she can feel better… Mommy can't eat.... It makes her tummy feel pain. You can still eat it though, because it is safe for you to eat."

4-year-old nephew: "Auntie doesn't feel good, her tummy hurts, Auntie can't play with you now."

5-year-olds: "Mommy's bladder doesn't work as well as it should and that sometimes I need to be able to use the bathroom often and be able to rest my body so it can feel well enough to play."

"Mommy has 'owies' in her bladder, and that is why I can't do everything or eat everything that he can eat. And he understands to some extent, and he will offer to get me snacks and drinks that I can have to share with him."

ICA OFFERS MANY PLACES OF SUPPORT FOR YOUR IC/BPS JOURNEY

ICA's IC/BPS Facebook Support Group

Have you joined ICA's "private" Facebook support group for the interstitial cystitis/bladder pain syndrome (IC/BPS) community? We are building an engaged group for Facebook users who are looking for a place to connect with others who are living with IC/BPS and their loved ones.

This group is moderated by the Interstitial Cystitis Association and currently has over 4,100 members.

We hope that you will join us! Go to facebook.com/groups/ICBPSGroup/ or search Facebook for "Interstitial Cystitis Association IC/BPS Support Group."

Let's support one another!

ICA's Online Support Community

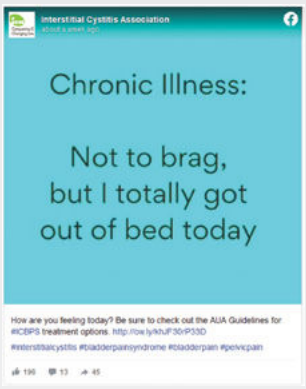
ICA's Online Support Community is a place of peace, hope, and support and provides comfort for patients, family members, friends, and healthcare professionals in search of better understanding the impact of IC/BPS.

This group is moderated by Inspire and currently has over 25,000 members. Don't miss out on the latest discussions from the ICA community. Below is a list of some current topics:

- Confused on diagnosis
- IC and cannabis
- Newly diagnosed and struggling

Together we're better Inspire

Join the growing ICA Online Support Community, where you can be connected to thousands of other people experiencing similar symptoms, situations, and emotions. Go to ichelp.org/support/onlinesupportcommunity/.



ICA Facebook Page

View this and other posts on ICA's Facebook page at facebook.com/InterstitialCystitisAssociation. With over 42,000 followers currently using this Facebook community, support is just a click away.

IC/BPS Support Groups

ICA is pleased to provide you with a list of IC, bladder pain syndrome (BPS), and chronic pelvic pain support groups in the United States. Go to ichelp.org/us-support-groups to search for a support group in your area.

Do you run an IC/BPS support group? If so, please share your information with us so we can post it on the ICA Support Group page. Want to publicize your next group meeting? Please email your information to icamail@ichelp.org 3-4 weeks prior to the meeting date.

ICA Healthcare Provider Registry

For many people with interstitial cystitis/bladder pain syndrome (IC/BPS), an effective treatment plan requires a team approach, including urologists and other physicians, nurse practitioners, physical therapists, dietitians, and counselors. The ICA Healthcare Provider Registry includes clinicians who have agreed to be a referral source for IC/BPS patients. Visit ichelp.org/support/healthcareproviderregistry/ to learn more.

Do you know of other healthcare providers who treat IC/BPS patients? Are you a healthcare provider who treats patients with IC/BPS and wants to be included in the ICA's Healthcare Provider Registry? Email your name, suffix, specialty, practice name, address, phone number, and website URL to ICAmail@ichelp.org with your request to be included in the ICA Healthcare Provider Registry.

Help Support ICA's Activities!

Give Hope. Change lives. Donate today to help the ICA continue to provide awareness, advocate for research, and sponsor educational events for those affected by IC/BPS. ICA is the only non-profit IC/BPS association and is a 501(c)(3) organization, EIN 13-3292137.

ica Conquering IC. Changing Lives.
Interstitial Cystitis Association

"I can tell him when I'm not feeling good and he understands, but he quickly forgets and wants me to play during times I cannot. I try to keep my bladder pain to myself because he is very empathetic and gets overly concerned when people aren't feeling well. I don't want my child stressed over my condition."

7 and 13-year olds: "They have asked how what I drink and eat affect how I feel so explained it to them like this…. It's like having a cut and pouring hot sauce on it when I eat something hot, or pouring vinegar on it if I eat something with that. That seemed to pain a better picture in their mind, and they understood a little better. Now when I'm walking funny or slow or saying ow, they say mom, are the cuts in your bladder hurting you today?"

8-year-olds: "I told them I was sick but not going to die, and I couldn't do everything other mums could do. "

10-year-old granddaughter: "I let her know if I have a good day and can do fun things with her. But most of the time, I have to tell her I can't make it because my body hurts too much."

11 and 13-year-olds: "I told them about my pain and discomforts and what causes it to flare and my diet changes to help prevent flare-ups and then briefly explained what IC/BPS was."

12-year-olds: "I'm in a lot of pain and I can't help you right now."

"I assure them I am okay when I can't get out of bed. I remind them that this is not fatal. Lots of hugs and I love yous… After a really scary flare or other health issues. I talk with them about how they were feeling, and how they are feeling now."

14-year-olds: "I wanted my son to know that when I told him I was going to the bedroom to do a bladder treatment and came out with empty bottles and all the things to throw away, I didn't want him to be scared."

Older teenagers: "I was focused on making sure that they did not hold back their emotions or anger because they didn't want to upset me or cause me more pain. I explained often that the pain had nothing to do with me and that they couldn't really make it worse (or better) and that they should not tie their responses or reactions to my pain."

21-year-old: "She hates that there's no cure. She worries with me that I'll be in pain the rest of my life."

23 and 25 year olds: "I tell them that I am frustrated because there are no answers and I think it worries them that I can't just go to the doctor and everything will be all right."

Above all, it's important to keep in mind that the journey of a condition like IC/BPS—the often long road to diagnosis, medical treatments, and diet and lifestyle changes—is a learning experience for the entire family. One parent who struggled with symptoms from childhood but wasn't diagnosed until her own children were in high school says, "Parenting them without knowing what was wrong with me was very difficult because I couldn't explain to them why I was the way I was." Another adds, "We talk about it and talk about how much we have all learned as a result of having to deal with my condition."

Tips for Difficult Times

The American Academy of Pediatrics offers tips for parents navigating stressful and potentially traumatic situations with their children—from divorce and death to anything that produces a chronically stressful environment. While they may or may not apply to every family living with IC/BPS, we've included some additional advice in brackets:

Parents and other loving adults are very important in helping children practice resiliency. Parents need to take care of themselves before they will be able to help their children, similar to the instructions heard on an airplane—"Put on your own oxygen mask before assisting others."

What does this mean?

- **Identify your circle of support.** Parenting is hard, especially when families have experienced difficult times. No one should try to do it alone. Who do you turn to for advice or help or just to talk about what's going on in your parenting? Seek support from counselors, physicians, family and friends, faith communities, and others who can help you see what you are doing well and to connect you with more support when needed.
- **Take care of yourself physically.** Eat healthy, get enough sleep, practice an exercise routine, take care of your medical needs and give yourself some child-free time to relax.
- **Identify things you love to do and make time for them.**
- **Identify ways that help you calm down or handle stress when it happens.** Take a walk, practice deep breathing, talk to friends, or meditate or pray.

Once parents have found ways to practice better self-care even in stressful times, they can provide support to their children. What does this support look like?

- **Be a positive influence in your children's lives.** Your children need to know that you love them and believe in them. Ordinary things like playing together and spending time together can help with this.
- **Learn about what you can and cannot expect from your children at different ages.** Use this knowledge to plan your activities. For example, a 2-year-old is not going to be able to sit still for long. When you need to bring your children to the grocery store, involve them: "Do you see anything red?" "Please help me put the cans into the cart." Or, if possible, consider going to the grocery store on your own, without your children, or going with a friend who can help.
- **Model good behavior for your children.** They look up to you and will try to do what you do.
- **A good parenting practice is to stay as positive as possible.** For example, give your children praise; try to notice the good things you see them doing each day.
- **[Keep your pediatrician informed. It may be a good idea to tell your child's healthcare practitioner that a parent has IC/BPS and that this may be a source of stress in their life.]** Medical professionals can help you and your children get the support you need. The earlier you get support for your children, the easier it will be for them to heal quickly and continue living healthy and less stressful lives.

Learn more at bit.ly/StressTips-AAP.

HELP KIDS HELP THEMSELVES. Parents with IC/BPS often prepare for their children when they're feeling better so they can take care of some activities on their own when they are feeling worse. Some put together a week's worth of clothes for their children, while others give theirs age-appropriate tools to help themselves.

"I leave a jar of milk in the fridge, a bowl, spoon, and covered bowl of cereal on the table for my 4-year-old," one says. "I have taught him to use the remote and the password to my phone." When children are older, "I buy and prepare food they can make and serve themselves. I also instruct the older kids, from the couch, how to make simple meals," another adds.

Afterschool routines are another helpful strategy. "The kids know what to do even if I am unable to tell them," one parent says. "We have a snack table where they can grab easy snacks that I don't need to prepare," another adds.

CREATE OPPORTUNITIES FOR TOGETHERNESS—EVEN AT THE WORST TIMES. "There are days you are in so much pain you can't get out of bed," one parent says. "So you try to do low-key activities with the children." Another agrees: "When I am unable to get out of bed, we do homework from there, reading, watching movies, talk, and play card games."

"I plan for things around the house like movie night, order out food of their choice night—anything I can do to feel like I'm a part of their lives," a parent adds.

Children can be surprisingly supportive in these cases, one parent says: "Most times, they are pretty sympathetic if they can tell mommy is hurting. Just being there is key for me, even if we just lie in bed that day and watch shows together. It's not ideal, but being kind to myself is important and I've had to learn not to feel guilty about this."

Conversely, it's important to celebrate on the days that are better, one parent says. "Sometimes I take time to pamper myself and take [my daughter] with me—to get nails done or something fun, like have a girls day…. We can spoil ourselves a little and celebrate those days when we are both feeling good."

SEEK HELP WHENEVER POSSIBLE. Parents pointed to the importance of spouses, family members, friends, neighbors—and even their own children—in helping support them and their family (see story p. 19). "Take help that is offered and don't feel guilty," one says.

PLAN FOR ABSENCES AND CHANGES IN PLANS. "It's okay to miss something because you aren't feeling well," one parent says. "Pushing through makes you feel worse and ruins the day and your memories."

CONSIDER MEALS CAREFULLY. A challenge for all IC/BPS patients, diet becomes more complex when planning for a family. "While it is very important to introduce all foods to children, it is very hard to fix healthy, good tasting meals for children when you have IC," one parent says. "I always have to fix many things because I could not eat a lot of foods I needed to introduce to my girls. I struggled with time management working and trying to have meals ready for busy children."

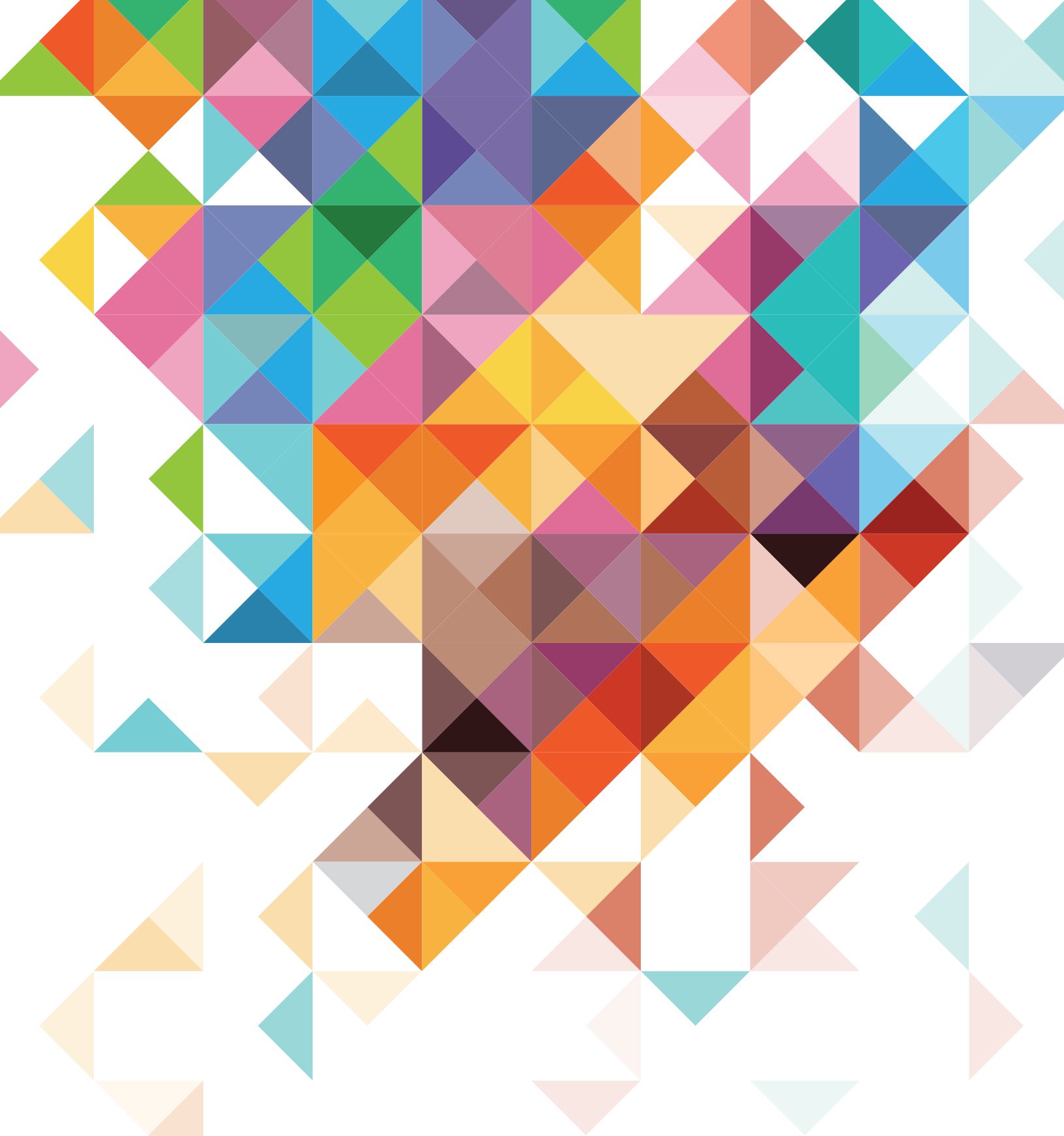
Others discussed bringing meals for themselves when going with their families to restaurants, although some say that understanding their own dietary triggers was the key to finding a better balance for everyone in the family. "Over the years I became aware of the foods I could not tolerate and which places were the worst for that food and I was able to choose places that offered choices that were good for all of us," one parent says.

ENCOURAGE CHILDREN'S RELATIONSHIPS WITH OTHER FAMILY MEMBERS AND FRIENDS. Research suggests that quality relationships with the other parent and peers can mitigate the impacts of parent chronic illness in adolescents. Beyond academic studies, parents with IC/BPS recognize that kids need time to live their own lives. "They need to enjoy being a kid/teenager," one survey respondent says.

REMEMBER THAT CHILDREN ARE RESILIENT. Says one parent whose children were 9 and 6 when they were first diagnosed, "I was grateful at how quickly they all adapted to my needs, which basically meant delayed time leaving the house whenever we were going somewhere, and always needing to find a bathroom wherever we were going." (See box, p. 20).

Open lines of communication can help when symptoms become worse. "My children and I were already very close so talking to my children about my new health issues was not hard," one parent says. Adds another, "the more they learn about IC/BPS, the more they'll be able to adapt."

Continued on page 20



Conquering IC.
Changing Lives.
Interstitial Cystitis Association

2022
Annual Report

2022 Annual Report

Conquering IC. Changing Lives.

Interstitial Cystitis Association

Throughout 2022, the Interstitial Cystitis Association continued its mission of advocacy, research, and education to improve the lives of the more than 12 million Americans suffering from IC/BPS.

• • • FROM THE EXECUTIVE DIRECTOR • • •

As it approaches nearly four decades of service, ICA remains the voice of the more than 12 million people in the interstitial cystitis/bladder pain syndrome (IC/BPS) community. In 2022, the association continued to deliver on its promise to advocate, educate, and support research to improve the lives of those with IC/BPS and ultimately find a cure.

Throughout the year, ICA provided educational offerings featuring healthcare providers, researchers, and IC/BPS patients. ICA's annual *Step Up for IC/BPS—ICA Awareness Walk,* as well as a self-guided Spring into Summer Self-Care Adventure, provided multiple opportunities to learn and educate others. Our newly redesigned website, ichelp.org, continues to emphasize these and other educational offerings, which can be accessed anywhere, anytime.

ICA continues to be the only organization representing the interests of IC/BPS patients on Capitol Hill. Along with our successful virtual Advocacy Days in May, ICA staff and leadership met with Congressional leaders and provided IC/BPS patients with the tools needed to educate their representatives throughout the year.

IC/BPS research took a large step forward with the first revision of the American Urological Association (AUA) clinical treatment guideline since 2014. ICA also highlighted opportunities for IC/BPS patients to participate in clinical trials, including efforts to ensure greater participation in research by historically underrepresented populations.

But it is you, our members, advocates, and supporters, that allow us to fulfill our critical mission of improving the quality of care and the lives of people with IC/BPS. With your help, we will continue to provide opportunities to connect, learn, advocate—and hope—for many years to come.

Thank you for your continued support. We can't do it without you!

With gratitude,

Lee K. Lowery, MPA, CAE
ICA Executive Director

Give Hope, Change Lives

The ICA is the only nonprofit organization dedicated to improving the quality of healthcare and lives of people living with IC/BPS and is a 501(c)(3) organization (EIN 13-3292137). Your support helps ICA provide advocacy, research funding, and education to ensure optimal dignity for people affected by IC/BPS. To learn more, visit ichelp.org/donate.

• • • ADVOCACY • • •

ICA advocates for the needs of the 12 million Americans with interstitial cystitis/bladder pain syndrome, as well as those of the healthcare providers, researchers, and others who work to improve the lives of IC/BPS patients. We also empower people with IC/BPS to advocate for themselves and to ensure we maintain momentum and awareness of the condition and those who suffer from it.

IC ADVOCACY: A YEAR-ROUND EFFORT

ICA Advocacy Days were virtual again in 2022, with ICA board members, staff, and volunteers holding meetings with Congressional offices May 23-25. But advocacy is a year-round effort, and ICA invited the entire IC/BPS community to participate by emailing and calling their representatives to educate them about IC/BPS and how it impacts their lives. Videos recorded by ICA leaders provided insight on how to communicate with lawmakers and the importance of personal stories. Learn more at ichelp.org/get-involved/advocate/participate-in-advocacy-month/.

ICA Leadership also met with Congressional leaders throughout the year to communicate ICA's legislative priorities and signed on to several letters as part of coalitions representing a broad range of patient advocacy organizations. Among the highlights:

• In March, ICA Chair **Mike Greenwell**, ICA Vice Chair **Laura Santurri**, ICA Executive Director **Lee Lowery**, and ICA's Washington representative met with **Rep. Rosa DeLauro's** (D-CT) office to present ICA's legislative priorities. Congresswoman DeLauro is Chair of both the full Appropriations Committee and the Labor, Health, and Human Services (LHHS) Subcommittee.

• In August, Greenwell, Santurri, Lowery, and ICA's Washington representative met with the offices of six Senate LHHS Subcommittee members ahead of their bill release to push for increased IC funding with the Centers for Disease Control and Prevention (CDC). Meetings occurred with the offices of **Sen. Joe Manchin** (D-WV), **Sen. Tammy Baldwin** (D-WI), **Sen. Marco Rubio** (R-FL), **Sen. Jeanne Shaheen** (D-NH), **Sen. Brian Schatz** (D-HI), and **Sen. Dick Durbin** (D-IL).

• Calling the COVID-19 pandemic "the earthquake that has triggered a tsunami of chronic disease," ICA signed on to a letter to the Healthy Future Task Force's Security Subcommittee, one of seven issue-specific task forces announced by U.S. House of Representatives Republican Leader **Kevin McCarthy** (R-CA). The letter, which was co-signed by nearly three dozen patient advocacy organizations, stressed that the United States has failed to adequately and consistently prioritize funding for the prevention of chronic diseases and conditions and the promotion of health and well-being, and that this failure has made our nation more vulnerable to severe illness and death from infectious disease.

• Joining forces with 33 other patient, provider, healthcare, and research organizations, ICA signed on to letters urging Congress to promptly pass the final Fiscal Year (FY) 2022 appropriations bills with a robust increase for the National Institutes of Health (NIH), including the work of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

ICA's 2022 Legislative Priorities

FY 2023 FUNDING PRIORITIES:

- **Provide $1,500,000 for the IC Education and Awareness Program at the Centers for Disease Control and Prevention** (CDC). This program promotes public awareness of IC/BPS through education for health care providers and the public. As a diagnosis of exclusion, physicians must be aware of IC/BPS for patients to receive timely and accurate diagnoses and this program maintains a significant focus on information sharing among stakeholders, with the aim to increase awareness, diagnosis, and proper treatment.
- **Provide the National Institutes of Health (NIH) with at least $49 billion in FY 2023.** The National Institute of Diabetes, and Digestive, and Kidney Diseases (NIDDK) leads the NIH research portfolio with groundbreaking studies like the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network which takes a whole-body approach to studying IC/BPS as well as epidemiology research.
- **Include "interstitial cystitis" as conditions eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) for FY 2023.** IC/BPS is becoming increasingly prevalent among veterans and is associated with post-traumatic stress disorder. Congress has historically included IC/BPS in the list of eligible conditions for research under this program, and IC/BPS researchers compete successfully each year.

2022 Policy Priorities:

Maintain access to chronic pain care medication and protect the patient/doctor relationship with regards to prescriptions. Chronic pain patients depend on important medications to cope with their pain. The vast majority of IC/BPS patients often suffer major and multiple quality of life issues due to this condition. Many IC/BPS patients are unable to work full time because pain affects their mobility, sleep, cognition, and mood. These are people that simply want to lead productive lives and need pain medication to do so. Due to the fact that IC/BPS is categorized as a non-cancer pain condition, IC/BPS patients already have a difficult time obtaining pain meds. IC/BPS doctors do not have time nor the inclination to effectively prescribe or monitor the distribution of the opioid class of medication and often refer their patients to Pain Management Specialists, many of whom have never heard of IC/BPS and often refuse to treat them. In addition, antidepressants and benzodiazepines are often used to treat both mood and sleeping disorders for IC/BPS patients.

ICA fully supports educating providers with the full spectrum of pain management regarding effective treatment for all patients. We understand the current epidemic with prescription misuse, abuse, and overdoses. However, we represent patients who rely on responsible use to live a normal life. Pain management is wide reaching and does not only include prescribing health providers but also physical therapists who assist patients working on their pelvic floor to alleviate and manage pain. These practices can lead to a patient moving away from prescription usage while maintaining the same quality and results of care.

ADVOCATE FOR IC/BPS PATIENTS!
Learn how at
ichelp.org/get-involved/advocate/

ICA RESPONDS TO PROPOSED 2022 CDC OPIOID CLINICAL PRACTICE GUIDELINE

ICA submitted comments on the Centers for Disease Control and Prevention (CDC) proposed clinical practice guideline, CDC Clinical Practice Guideline for Prescribing Opioids—United States, 2022, in April, stating that it "fully supports educating providers with the full spectrum of pain management regarding effective treatment for all patients."

"More research needs to be done for effective non-opioid treatment options before further limiting an already very limited pain management protocol," the ICA statement says.

The proposed guideline "is not intended to be applied as inflexible standards of care across patient populations by healthcare professionals, health systems, third-party payers, organizations, or governmental jurisdictions," the CDC's summary of the proposed guideline states. "The guideline is intended to achieve the following: Improved communication between clinicians and patients about the risks and benefits of pain treatment, including opioid therapy for pain; improved safety and effectiveness for pain treatment, resulting in improved function and quality of life for patients experiencing pain; and a reduction in the risks associated with long-term opioid therapy, including opioid use disorder, overdose, and death."

• • • RESEARCH • • •

ICA advocates for government funding dedicated to IC/BPS research, and helps keep the research focused on patients by serving on research steering committees and panels.

AUA IC/BPS GUIDELINES REVISED

The American Urological Association (AUA) revised its clinical guidelines on the diagnosis and treatment of interstitial cystitis/bladder pain syndrome (IC/BPS) for the first time since 2014. Released in May 2022, the new guideline emphasizes that treatment must be "individualized and based on the unique characteristics of each patient" and based on "shared decision-making" between healthcare providers and patients, the AUA said in a statement.

To that end, the updated guideline no longer ranks treatments from first-line through sixth-line tiers "in order to emphasize that shared decision-making, individual patient factors, and clinical judgment are the most important factors in treatment choice." Instead, the guideline urges "concurrent, multi-modal" treatments across multiple categories, taking care to stress that the options listed under each category are not in any recommended order.

ICA has and will continue to share information about the guideline to patients and practitioners alike. "This guideline is meant to provide direction to clinicians and patients on how to recognize, diagnose, and treat IC/BPS. An important component of that clinical framework is discussion of treatments that should and should not be offered. As the relevant science evolves and improves, this guideline will continue to require amendment to remain consistent with the highest standards of clinical care," said **J. Quentin Clemens, MD**, chair of the AUA guideline amendment panel and director of female pelvic medicine and reconstructive surgery fellowship at the University of Michigan.

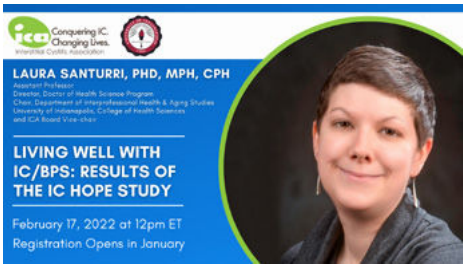
ICA, BOSTON CHILDREN'S HOSPITAL, BLACK HEALTH MATTERS COLLABORATE ON IC/BPS RESEARCH STUDY

In the last year the ICA has played a pivotal role in IC/BPS research at Boston Children's Hospital. From advertising natural history studies to recruitment for genetics analyses, the ICA has been involved in every aspect of the hospital's Center for Disease Control (CDC) and Columbia University O'Brien Center for Benign Urology grants. More than 1,500 individuals responded to the demographics survey, driven by ICA's extensive network and effective recruitment. The results of this survey have already led to several papers being prepared.

ICA also is working with Inspire, Boston Children's Hospital and Black Health Matters (BHM) on diversity and inclusion in IC/BPS research. The collaboration is intended to ensure that all types of individuals are included in research efforts, as underrepresented patient populations continue to be highly underrepresented in research studies. ICA, BHM, Inspire, and Boston Children's Hospital (BCH) encouraged these groups to participate in the survey.

LIVING WELL WITH IC/BPS: IC HOPE STUDY RESULTS SHARED

In February, ICA Vice Chair **Dr. Laura Santurri** shared during an ICA webinar the results of the IC Hope Study that she conducted with colleagues at the University of Indianapolis. The purpose of the study was ultimately to better understand how people living with IC/BPS are coping with the condition in effective ways.



To watch the ICA webinar, visit youtu.be/1zUlbKBmPB8.

ICA RECRUITS FOR TEXT-BASED CLINICAL TRIAL

ICA helped recruit patients to participate in a research study conducted by the **University of Pennsylvania's Division of Urogynecology**, which is evaluating a smartphone-based program that teaches patients how to self-manage symptoms.

Short for Educational Remote IC/BPS Aide, ERICA delivers text-based reminders and video modules on evidence-based, holistic self-care strategies and provides support through check-ins that include an option to talk to a clinician.

ICA ENCOURAGES APPLICATIONS TO FDA PATIENT ENGAGEMENT COLLABORATIVE

ICA encouraged IC/BPS patients and those who support them to apply as new members of the **Food and Drug Administration** (FDA) Patient Engagement Collaborative (PEC). The PEC is a group of patient organizations and individual representatives who discuss ways to enhance patient engagement. The PEC is made up of patients who have personal disease experience, caregivers who have personal experience supporting someone with a health condition, and representatives from patient groups who have direct or indirect disease experience.

ICA arms patients, healthcare providers, caregivers, researchers, and the general public with objective and up-to-date information about IC/BPS.

VIRTUAL WALK FOR IC/BPS RAISES $28,000, SPREADS AWARENESS

The ICA 2022 Virtual Fall Fundraiser - Step Up for IC/ BPS Awareness and Educational event that took place online—and everywhere—September 19-24, raised over $22,000 for greater IC/BPS awareness, better treatments, and an eventual cure for IC/BPS.

For the third year running, participants came together virtually for the annual *Step Up for IC/BPS—ICA Awareness Walk*. Over 180 participants took more than 2.5 million steps during the virtual walk. The **Toth Family** and **SPX Corporation** matched individual donations up to $5,000 each to triple the impact for the third consecutive year.

Participants received information on the updated American Urological Association guidelines for IC/BPS, sexual health, pelvic floor physical therapy, health insurance, and other video offerings, all while working to raise awareness and funds for better IC/ BPS care everywhere.

Sponsors who helped make the 2022 Fall Fundraising, Awareness and Educational event a success included **Algonot Cysto Protek, Desert Harvest,** and **West Coast Mint**. IC/BPS professionals who provided expert educational content included **Dr. Robert Moldwin, Dr. Nicole Cozean, Tacha Kasper, MA, LMFT, Dr. Reza Sharif** and **Heather Florio, Dr. Tony Buffington,** and **Dr. Alexandra Milspaw**.

Watch videos of educational content at bit.ly/ICAExpertVids.

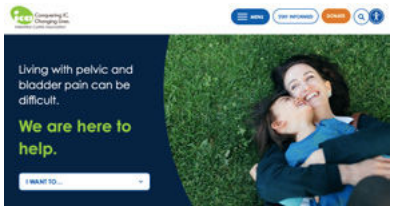
It's not too late to support *Step Up for IC/BPS!* Visit bit.ly/ICAStepUp22, or to learn more about how to start an IC/BPS awareness walk in your own community, visit ichelp.org/walk-for-an-ic-cure/.

4TH ANNUAL CARTERSVILLE, GA STEP UP FOR IC/BPS WALK RAISES $4,700

Dr. Jeffrey Proctor and his team at **Georgia Urology** hosted the fourth annual Cartersville, Georgia, *Step Up for IC/BPS – ICA Awareness Walk* on Saturday, September 24. Thanks to dedicated and passionate participants and donors, the event raised over $4,700.

We would like to extend our gratitude to the event sponsors who helped make the 2022 awareness walk event a success: **Georgia Urology** and **Dr. Jeffrey Proctor, West Coast Mint** and **180° Medical**. Shout out to our top individual fundraiser, **Aubrey Williamson,** and to our top team fundraiser **The Stream Team**—we are so grateful for your support!

ICA LAUNCHES NEW WEBSITE



ICA announced the launch of its new website at ichelp.org. We hope you find our new website to be more user-friendly and easier to navigate, with access to resources and information about IC/BPS, as well as ways to get involved.

ICA'S SPRING INTO SUMMER SELF-CARE ADVENTURE NOW AVAILABLE TO ALL!

ICA held a **Spring into Summer Self-Care Adventure**, a free virtual and interactive five-day self-care journey, during which more than 400 participants earned points by completing self-care activities and raising critical funds and awareness about IC/BPS.

The videos are now available to the entire IC/ BPS community at bit.ly/SelfCareVids. They include PT Self-Treatment at Home, **Dr. Nicole Cozean**; Desert Harvest: Research Interview with **Dr. Lenore Ackerman** and **Heather Florio**; **Inspire Online Support Community:** Bladder Health Survey; Trauma-Informed Yoga Class with **Mia Tarduno**; Living Well with IC/BPS: The Results of the IC Hope Study; ICA's Online Support Groups; and Mindful Journaling: Share Your Thoughts with Mindful.

ICA BOARD MEMBER REPRESENTS IC/BPS COMMUNITY AT AUA BLADDER HEALTH ALLIANCE

ICA Board Member and IC/BPS patient **Claudia King** served as a panelist for a women and bladder health session during the American Urological Association's Bladder Health Alliance Roundtable. During the AUA event, King discussed how difficult it is for a woman to get a diagnosis of IC/BPS and other barriers to care and stigma associated with the condition.

IC/BPS IN NATIONAL MEDIA

To spread awareness of IC/BPS, it is essential that people are exposed to it in the media. ICA highlighted examples of national media coverage, including:

Bachelorette Star Diagnosed with IC/BPS

Angie Kent, former star of the *Bachelorette* TV series, revealed that she has been diagnosed with IC/BPS. The 34-year-old, who starred in the Australian version of the show, said on her Instagram account that "I have a new diagnosis, interstitial cystitis.... This is a marathon, not a sprint." Other IC/BPS patients responded, offering support and words of advice. Read Kent's Instagram post at bit.ly/IC-Kent.

IC/BPS Goes Viral on TikTok

Breanne Rodgers has more than 450,000 followers on the TikTok viral video platform, so when the 21-year-old Alabamian posted a video from her car about her yearlong experience trying to get diagnosed after having "constant UTIs," more than 1.1 million people wound up viewing it. Hundreds of other IC/BPS patients also responded with advice on diet and support. "As painful as it is, it's so, so comforting to know other women have this," one said.

View Rodgers' video at bit.ly/TikTok-ICBPS, or read an article about her experience at yhoo.it/3wJMFSF.

Black Health Matters: Meet 'James'

"James" (real name changed for privacy purposes) shared his IC/BPS story with **Black Health Matters** to increase awareness. Read more at

blackhealthmatters.com/personal-bladder-health-story-interstitial-cystitis.

HERE FOR YOU IN 2022 AND BEYOND

ICA continues to serve the IC/BPS community, with many free resources online 24/7 at ichelp.org. They include:

- ICA's IC/BPS Facebook support group facebook.com/groups/ICBPSGroup/
- ICA's Online Support Community inspire.com/groups/interstitial-cystitis-association/
- ICA's Facebook page facebook.com/InterstitialCystitisAssociation
- IC/BPS support group directory ichelp.org/us-support-groups
- ICA healthcare provider registry ichelp.org/healthcare-provider-registry
- Ask an IC Question page ichelp.org/ask-an-ic-question
- Staff and volunteer support at icamail@ichelp.org or 703-442-2070.

FINANCIAL STATEMENT

Making the Most of Limited Resources

In 2022, the Interstitial Cystitis Association (ICA) continued its mission as a steward for resources for programs and services that directly support education, advocacy, and research for IC/BPS. A summary of financial statements incorporated in the annual audit report issued by Rogers & Company for the fiscal year ended September 30, 2022 will be available in the "About Us" section of the ICA website, www.ichelp.org.

2022 ICA BOARD OF DIRECTORS

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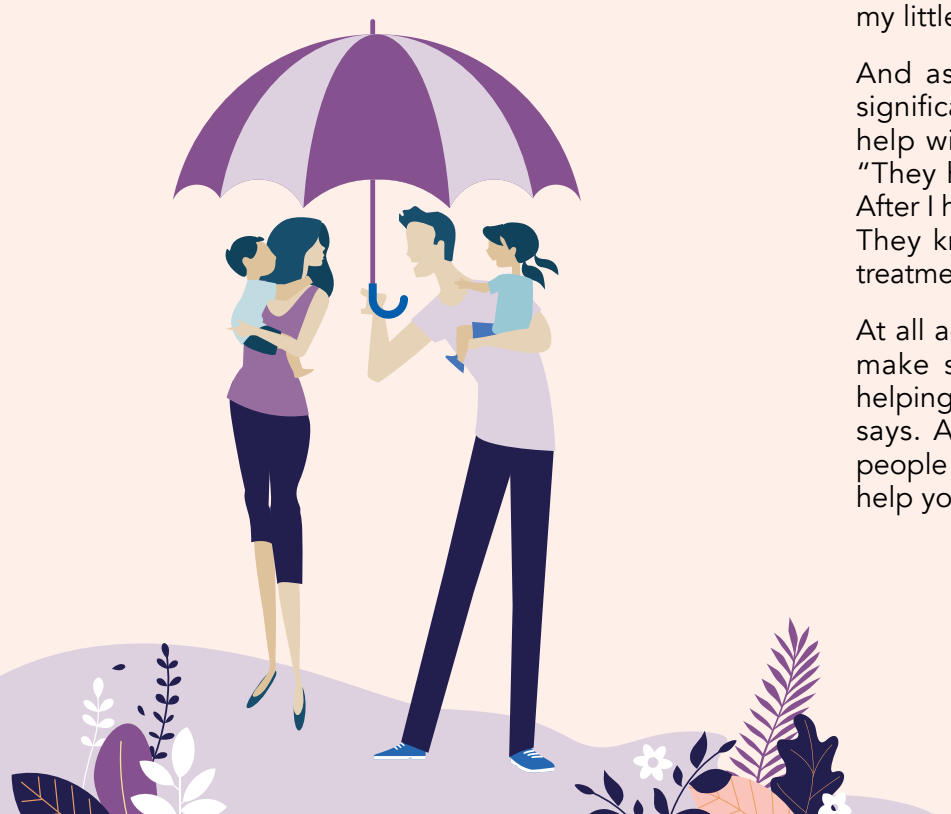
Support of All Kinds

It takes a village—another parenting adage that takes on special meaning for parents with chronic conditions like IC/BPS. As one says, "enlist all the help that you can!" Another adds, "It's not a sign of weakness it helps you to be able to make it to tomorrow," another parent says.

Survey respondents list a wide range of supports—extended families, church communities, neighbors, house cleaners, and more. "Each family plays a different role in my kids' lives," one parent says of her church and extended family. "They pick up, babysit, bring meals, take the kids out to places, keep me in prayer. They check in with the kids and how they are feeling… Couldn't do it without them."

But most focused on their spouses, and often, their children. "My husband and I are a great team—there are no his or her jobs, we both just do what needs to be done," one mother says. "When I am down, he helps me; and I help him when he needs it." A father adds, "my wife is a nurse, so I have been very fortunate that she understands my problem!"

Spouses and partners help carry the weight—at times, literally. "He will help carry the 3-year-old when I can't—any sort of heavy lifting when I tense my core creates a flare," one mother says. They also can support each other when flares make it difficult to parent.



However, some parents stress the toll that IC/BPS took on their relationships, leading to a lack of support and in some cases separation. "If I could give anyone with IC/BPS advice, it would be to find a supportive spouse," one says. "Your journey will have many tough times and having someone who loves you just as you are and is willing to help you through the good times and the bad is imperative." Another adds, "it is so important to know your IC/BPS isn't the only thing that defines you. Pick someone who is amazing enough to know that too."

Many parents also point to how their children provide support. One 31-year-old parent says their children—ages 7 and 13—help with house chores and bring ice packs when the pain is at its worst. "It kills me inside some days to know they had to grow up a little faster and do more things for themselves… Thank goodness that I have great kids who support me."

In particular, older siblings can help support their brothers and sisters. "The older kids help the younger till my husband gets home from work," one mother says. And as they get older, kids can help parents by becoming more independent—doing their own laundry, preparing meals, and taking on other chores that help reduce stress for parents. "Once they began to drive, a lot of my pressure was relieved as they depended on me less," one parent says. "Now I am watching my little grandchildren several times a week. "

And as adults, grown children can provide significant support. "Both my kids are a huge help with my IC/BPS now," one parent says. "They help me when I physically can't move. After I have surgery they're right there assisting. They know my routine after each surgery or treatment. They've grown up with me having it."

At all ages, it's important to "praise them and make sure they know they're important to helping you get back to remission," one parent says. Adds another, "surround yourself with people who know your pain is real, and that will help you through the tough times."

SILVER LININGS

Research studies and parents alike point to the silver linings of children with parents facing chronic conditions like IC/BPS, including greater resiliency and empathy for others. Says one parent, "my boys grew up fast! They were more adult acting and understanding than their own father."

Parents say the key to building that resiliency stems from their own approach to parenting—and how they approach their own conditions. "I am certainly blessed to have such loving and supportive children. And I believe it's because I've always been loving and supportive to them even on my worst and painful days," says one. "I always tried to stay positive no matter of the outcome to any situation, especially if it wasn't in my favor, and they witnessed that sentiment and I feel learned from it and now they have good attitude and understanding and a very caring nature towards others as well."

"I have tried my best to make sure my children did not feel singled out or left behind because of my illness," another adds. "Children are resilient and can adapt to anything as long as you present issues with a positive attitude."

Continued from page 12

DON'T OVERLOOK YOUR OWN CARE. "Seek treatment until you find what works," one parent says. Another says that mindset extends to daily life: "Self-care even without IC/BPS is important."

"Take care of yourself first. Make sure you get enough sleep, eat healthy food, stay hydrated, enjoy the little things," another parent says. "The important part is to let your kids know you love them and want the best for them. Don't play the victim."

Parents also can involve their children in self-care. "Sometimes I need to stretch and I get my boys to join me for a short while," one parent says. "Make massages and stretching a daily routine for everyone," another adds.

GIVE YOURSELF GRACE. "We can only do what we can do. Sometimes that seems like it is not enough, but it is," one parent says. "Kids are going to be kids. They are going to have their feelings and emotions. Don't let guilt take over, and don't parent from guilt."

"It's okay to not be the perfect parent," another adds. "If you need time to yourself, it's okay if your kids get a little more screen time."

It's important to expect anger from children at times, parents say. "[They] may say things they don't mean out of frustration, fear and feelings of hopelessness," one parent says. "Give yourself grace."

DON'T COMPARE YOUR FAMILY TO OTHERS. Sound advice for all parents, this adage applies particularly for families navigating a chronic illness like IC/BPS. "Everyone's situation and family dynamics are different," one parent says. "You have to do what works best for you and your family."

BE POSITIVE. Look at parenting as an opportunity to focus on something beyond IC/BPS. Says one, "my children are honestly what keep me going. They keep me moving, they are my distraction in the best way, and they keep me positive. I try to stay positive for myself to keep out the stress and anxiety. Those both cause flares for me and make me feel worse."

ALL IN THE FAMILY: PARENTS AND CHILDREN WITH IC/BPS

It's the worst nightmare of any parent—watching a child develop a medical condition of any kind. With IC/BPS, it's particularly cruel. While the specifics of the hereditary nature of IC/BPS continue to be explored, a significant number of parents who responded to the *ICA Update* survey said their children also developed the condition. One recalls that her mother was never diagnosed with IC/BPS, she was, and her 37-year-old daughter now has it.

"I feel horrible that I gave this to her," another parent says. Another spoke of her daughter being diagnosed with vulvodynia in her mid-twenties "and seeing her suffer in some of the same ways I have." Yet another says her adult daughter has chosen not to have children because of IC/BPS.

It's not just IC/BPS—a 2011 study published in *Academic Pediatrics* found an estimated 43 percent of school-age children in the U.S.—some 32 million—have some sort of chronic health condition. Eight percent of children between 5 and 17 have chronic conditions that limit their activities, according to the National Health Council. And parents of children with chronic conditions must also focus on self-care: A meta-analysis of research studies suggests that parents of children with chronic conditions have poorer mental health and, particularly among women, a greater risk of cardiovascular disease and overall mortality.

Parents play a key role helping children navigate chronic conditions. Says one whose 12-year-old has begun showing some of the symptoms of IC/BPS, "we are starting to get into more detail—manage stress, stay away from sodas, etc." In return, children with similar symptoms can provide support as well. One parent goes to the urogynecologist with her 19-year-old daughter. "We discuss our daily pain levels and how to treat the pain and urgency," she says. Says another parent whose 29-year-old daughter was just diagnosed with IC/BPS, "we both do a lot of research and buy cookbooks, share information, and I listen to her as much as possible. While listening, I'm able to understand what she is going through. I just listen, no judgment, no interrupting."

'BREATHE DEEPLY'

Above all, parents stress the importance of staying focused on family. Says one mother whose doctors discouraged her from having children, "having kids… keeps me the strongest. I look into their eyes and know they need their mom. I know my job is not done here."

The parents who responded to the survey returned time and time again to the idea of balance—and the importance of developing an atmosphere of honesty and trust. "Don't keep your family in the dark about IC and what you are feeling, but don't let your illness be the thing that defines you, if possible," one says, noting that conveying that the condition was "difficult but manageable" for many years "helped influence how my children thought about my illness."

"I let them see me in pain, and I let them see me cry because this is life and I can't always protect them from pain. They need to know it can happen," another mother says. "However, I tell them, 'Mommy is strong and I will be okay. It may just take time but I will be ready to play when the pain is gone!'"

Above all, remember that time is fleeting—for children and parents alike. "Breathe deeply. They are young once and then it is gone," one parent says. "Sometimes getting into the moment with your children helps you forget the pain."

Mark Toner is editor of ICA Update.

Watch for more articles on parenting with IC/BPS throughout the year.

The Power of a Personal Story

Advocating for IC/BPS with federal and local lawmakers is critical. Your own story can make a difference.

Educating lawmakers about IC/BPS is essential to ensure that there continues to be funding for greater education, research, and ultimately a cure. One of the most powerful ways of doing so is perhaps the easiest—telling your own story. Like many people we come into contact with in our daily lives, lawmakers may never have met or known another person with IC/BPS, and our stories help make the condition—and the urgent need for greater support—real. As an example of what can be done, Shelley Kardon, an IC/BPS patient and member of the ICA Board of Directors, shared her own story:

It happened out of nowhere.

One day in December of 2000, I was perfectly fine. The next, I had unbelievable stabbing and searing pain in a place that no one wanted to talk about.

I will never forget the morning "it" happened. I felt the urge to urinate, and afterwards, immediately felt like I needed to go again. I would urinate every five to ten minutes. I felt burning pain. Nothing alleviated my suffering or gave me relief.

I went to my physician thinking I had a urinary tract infection. He treated me with antibiotics that did not help. My pain got worse. As time went on, I was having difficulty sitting, standing, and lying down. I had trouble sleeping. Everything I ate seemed to make me feel more burning. People would look at me and ask if I was okay, but I did not know how to respond. What was I going to say? It hurts where I urinate!

My life was turned upside down.

Once an active young woman, I was no longer able to exercise. I also had challenges working and took countless sick days. At the time, I was looking for a new job but was unable to pursue one. My entire life was put on hold indefinitely.

I went to numerous physicians who seemed baffled. I found one doctor where I lived who treated IC/BPS. A hydrodistension finally confirmed my diagnosis. I was panic stricken because I knew through extensive personal research that IC/BPS had no cure.

Over the next four years, I tried every treatment possible including dietary changes, medications, physical therapy, acupuncture, and bladder instillations. Some helped a bit, but never quite took my pain away. Eventually, I found a medication that helped me and along with pelvic floor therapy, I was able to get better.

I felt hope the day I found the ICA.

I remember contacting the ICA years ago when I had pain. Everyone I spoke with was so helpful. It really made a difference to know that someone cared. Today, I have occasional flares but can live a more normal life. With the ICA's resources, I researched and educated myself about IC/BPS and worked with physicians, physical therapists, compounding pharmacies, and a pharmaceutical company to resolve my IC/BPS pain. Throughout my journey, they gave me the tools I needed to learn how to navigate this complex health issue.

I decided I wanted to make an impact and joined the ICA board of directors because we are the only non-profit organization that exists to support the IC/BPS community. My hope is that the ICA can continue to advocate for IC/BPS research dedicated to discovery of a cure and better treatments, raise awareness, and serve as a central hub for healthcare providers, researchers, and patients. I want to put an end to the debilitating pain that men and women suffer from with IC/BPS.

To learn more about how to tell your own story, visit ichelp.org/get-involved/advocate/participate-in-advocacy-month/.

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:** support.ichelp.org/store
- **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
- **Voices of Hope Blog:** ichelp.org/voices-of-hope-blog/
- **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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'Medical Gaslighting'

Studies have long shown that women—and especially women of color—have a harder time being diagnosed with a wide range of conditions and prescribed pain medication. This comes as no surprise to many with IC/BPS who have faced long roads to diagnoses and treatment—in a recent *ICA Update* survey, patients reported that on average, it took 4.5 doctors and 5 years and 7 months to reach a diagnosis.

However, the issue has gained higher visibility on social media and elsewhere, where it has been dubbed "medical gaslighting."

"Gaslighting is real; it happens all the time. Patients — and especially women — need to be aware of it," said Dr. Jennifer H. Mieres, a professor of cardiology at the Donald and Barbara Zucker School of Medicine at Hofstra/Northwell and coauthor of the book Heart Smarter for Women, told *The New York Times*, which received more than 3,000 comments, many of which involved personal experiences with gaslighting, after publishing an article on the phenomenon.

Here are five things that experts told the *New York Times* could be "red flags" in encounters with healthcare providers:

1. Does your provider continually interrupt you?
2. Does your provider minimize or downplay symptoms?
3. Does your provider decline to order imaging or lab work to rule out or confirm a diagnosis?
4. Is your provider rude, condescending, or belittling?
5. Are your symptoms blamed on mental illness—but not followed up on with a mental health referral or screening?

Among the ways of addressing the issue, according to the *New York Times*:

1. Bring detailed notes and records to appointments.
2. Prepare in advance with a list of points that outline the reason for your visit.
3. Prepare a list of questions to ask your provider.
4. Bring a family member, friend, or relative for support.
5. Stress that you want to leave the appointment with next steps for diagnosing or ruling out different possibilities as well as potential treatment options based on those possibilities.

If these strategies don't work, options include seeking a second opinion, considering switching healthcare providers, or reaching out to patient support groups like the ones for IC/BPS found at bit.ly/ICBPSsupportgroups or ICA's virtual options on p. 9.

Read more at bit.ly/NYTgaslighting (subscription may be required).

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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.

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