



# ILKA ROSS

*IC/BPS Warrior*  
*ICA Board Member*



## My Journey With IC

My name is Ilka and I am not only an ICA board member but an IC patient. For September's IC Awareness Month, I would like to share my journey with what was once a debilitating disease as well as tips and resources that have helped me learn to not only cope but to thrive as an IC patient.

I acquired interstitial cystitis 8 years ago, immediately following the birth of my 2nd daughter. I still remember the confusion and fear I felt as the labor and delivery nurse explained that my bladder was not functioning in the capacity it had been doing just the day before. I had just birthed my daughter, and as you are instructed to do after birth, was trying to use the restroom. Due to pressure and pain, I assumed I was relieving my bladder but I'll never forget my concerned nurse's face when she looked at me and said "I'm sorry, but there isn't anything coming out....". I tried several more times with only pain and pressure. Though our hospital visit included several painful urinations and catheterizations, I was far too occupied with the fact that my daughter had an eventful birth and was admitted into the NICU where she stayed for a week.

Upon arriving home, my bladder seemed to improve. Months passed with complete normalcy until suddenly there was a heaviness feeling in my bladder. Within a few more days the intense pain I had after labor had returned. Following everyone's recommendations, I spent the next 2 weeks drinking cranberry juice and taking AZO but the symptoms worsened. I decided I would stop by immediate care for a quick visit and antibiotics. The nurse ran the culture and came back with the results. No bacteria but white blood cells were present. She diagnosed me with an UTI, stated that I was drinking so much, in an attempt to help my symptoms, that I was diluting the bacteria too much for the test to recognize it, and gave me a prescription for antibiotics. This exact situation would transpire another 8 times, with different providers, over the next year.

Fast forward to the summer before my daughter's 2nd birthday and I find myself having the urge to urinate 24/7. When I attempt to relieve my bladder, I feel excruciating pain. I am up all night trying to use the restroom. 15 times a night to be exact. There wasn't much improvement during the day either. I was visiting the rest room an average of 60 times a day. I couldn't go 20 minutes without revisiting the restroom. The pain was so intense that the hair on my arms would stand on end. I had been using a heating pad to soothe my urethra pain to such an extreme extent that my thighs had dark marks where the skin was being affected by the constant heat.

My LAST-DITCH attempt for help came after snuggling my youngest to sleep and having a spasm so intense that I wet the bed. Her bed. I felt so defeated in that moment. How did things get so bad? I was unsure of how to make the 45 minute drive to my gynecologist but felt I had no other option. I called his office and made my appointment. During my many routine trips to the bathroom that night, I tried to map out my plan to make it to my appointment. At that time, I couldn't drive or leave my home because of the pain and constant urge to use the restroom. I decided the following items were essential to make it: a change of clothes for myself, the pads I was now wearing due to leaking, cranberry juice, AZO, and snacks for my babies. It took us well over an hour with more than five stops but we finally made it.

My doctor immediately had me fill out a questionnaire, one that would eventually become common practice at my urologist visits. Upon the return of my urine culture results and review of the questionnaire, my gynecologist says, "I believe you have a disease called interstitial cystitis and unfortunately your road to recovery is not going to be an easy or cheap one" and then refunded my co-pay. For 2 years I had assumed it was a mistreated UTI and would be healed after this doctor appointment. Realizing this wasn't going to happen was devastating.

I did as everyone with a smart phone does and "researched" obsessively for the next 2 weeks. I found an IC specialist, Dr. Proctor, and made an appointment for the following month. Finding this provider, and his nurse practitioner Brandy Knight, was a life changer. I was informally diagnosed at my first visit and formally diagnosed after my second visit/ cystoscopy. My bladder has all the typical signs of IC including inflammation and scarring. This would mark the beginning of my treatment journey. I was prescribed several medications in the beginning that had no effect on my disease, and though I was warned that this would probably happen, at times was very disheartening. With Dr. Proctor and Brandy's support and advice I was able to attempt several routes of treatment and would see a great deal of improvement within 1 year. I kept a food diary (for over a year), started following a strict IC diet, took my prescribed medications (Elmiron, Amitriptyline, Zyrtec, tamsulosin, and bi-weekly rescue treatments of heparin/lidocaine/sodium bicarbonate), and worked on managing my stress. By the 1 year mark, my symptoms had improved by 30% and continued to do so yearly until finally reaching remission in 2023.



## Motherhood and IC

IC is not an element that I thought would be added into parenting but nonetheless I found it being forced in. I quickly learned to pack extra outfits in case of accidents, including my child's. Sundresses and panty liners were a must for a very long time. I involved them in cooking new IC friendly recipes and made sure we had the best basic recipes like cupcakes and ice cream down pat. When going to close friends and family members' homes for playdates I would bring along my heating pad, to lay across my bladder, and increase the amount of time I could sit and chat with them. I had more conversation of "thank you for wanting to share your cookie but Mommy can't eat that right now" and "remember we don't touch anything in a public restroom, ever!" When I was in the thick of it, I was heartbroken that this was our new "normal" but as I look back, IC was not a part of motherhood I had planned, and it took a long time to navigate but I do feel that it taught me to give my body grace.

## Finding Support

During the early season of diagnosis, I found myself feeling lonely and overwhelmed. I had more questions by the day but struggled to find any answers. I was only aware of one other IC patient and things that were supposed to be supportive, such as automatic medical supply shipments felt insincere. I turned to the ICA Facebook page to find people like me. I followed every post and comment for months. The members of the group helped me feel included in a community. I found a lot of helpful suggestions and more importantly, I found kindness and empathy. It was the help I desperately needed. Also, since my diagnosis I have married a wonderful man, who has helped me learn what support looks like for me. He has learned a plethora of IC friendly recipes, since I'm an atrocious cook and found changing my diet overwhelming. He attends my doctor appointments and voices the concerns he has and symptoms he has noticed. He helps navigate teaching our children my limitations or diet restrictions. And arguably his best contribution, is teaching me to love the body I am in by loving it himself. Finding your support system, whether online or in person, with family or with support group members, is vital. Your people are out there and waiting to support you in the way you deserve.

## My Unsolicited Advice

Through all my trials and tribulations with interstitial cystitis, I believe the most valuable lesson that I have learned is: healing is not a linear path and it will not mirror anyone else's journey. The battle we face will not be the same as those around us. It is possible that we will regress, require a more intensive treatment, and some may heal quicker than us... and that is ok. Your body is not in a race with anyone. Your body is not failing when it needs more time to heal. Your body is not broken when it needs more help to heal. It's also okay to feel disheartened when our path becomes harder to navigate. It's okay to cancel plans when you need to rest and not only is self-advocating okay, it's recommended. Always remember, our journey to healing will be ours and ours alone.

**“The struggle of life is one of our greatest blessings. It makes us patient, sensitive, and Godlike. It teaches us that although the world is full of suffering, it is also full of the overcoming of it.”**

**– Hellen Keller**

## Resources

Through my journey with IC, I've been blessed to find many items that help me navigate IC. Links provided below: No affiliation codes or Sponsorships.

- **Cystex Dual Action Pain Relief** <https://a.co/d/8EYMYBC> -Favorite website to order medical supplies: <https://www.allegromedical.com>
- **Doctor Recommendation:** Urologist Dr. Proctor and nurse practitioner Brandy Knight in Cartersville Georgia.  
<https://www.gaurology.com/>
- **Favorite heating pad:** <https://a.co/d/9s8U0qG>
- **Food journal page for IC patients:**  
[https://www.canva.com/design/DAGMkUUIpqg/iv3gApTa\\_z0F8T0zQopkPw/edit?utm\\_content=DAGMkUUIpqg&utm\\_campaign=designshare&utm\\_medium=link2&utm\\_source=sharebutton](https://www.canva.com/design/DAGMkUUIpqg/iv3gApTa_z0F8T0zQopkPw/edit?utm_content=DAGMkUUIpqg&utm_campaign=designshare&utm_medium=link2&utm_source=sharebutton)
- **IC recipe page:**  
[https://www.canva.com/design/DAGMkTtIQGA/7pgSOEIJ7vuoHUST1LXefQ/edit?utm\\_content=DAGMkTtIQGA&utm\\_campaign=designshare&utm\\_medium=link2&utm\\_source=sharebutton](https://www.canva.com/design/DAGMkTtIQGA/7pgSOEIJ7vuoHUST1LXefQ/edit?utm_content=DAGMkTtIQGA&utm_campaign=designshare&utm_medium=link2&utm_source=sharebutton)
- **IC recipe website:** <https://icfriendlyrecipes.blogspot.com/?m=1>

