



CAROL DAVIS

IC/BPS Warrior



An Interview with Carol Davis

What year did you find out about the ICA?

I first learned about the ICA around 1995.

Have you witnessed any significant changes or milestones within the organization?

I have. The most significant relates to the way the patient population is being served with the advances in technology.

Can you share with us how your journey with IC/BPS has inspired your dedication to support the ICA through the years?

Shortly after my diagnosis, I began to look for information and support. I learned that the closest ICA support group was nearly 100 miles away but decided to attend a meeting anyway. With the help of the ICA, I held my first support group meeting within 6 months of my diagnosis. I attended an ICA convention in 1998 in Arlington, VA after which I became inspired to try to reach more patients. I organized the first Northern CA support group meeting with the help of my urologist, Christopher Payne the following year and was soon coordinating support for patients throughout CA. In 2000, I was hired by the ICA as the National Volunteer Services Coordinator. I held that position for 2 years until it was eliminated through downsizing. I have continued to support the ICA through the years.

What inspires you to be a monthly donor – can you share with others why being a monthly donor is important to you?

IC/BPS has continued to be a part of my everyday life since day one with only two brief periods of remission during the first five years. Throughout the years, I have participated in many research studies and clinical trials, always striving to keep informed of new developments and treatment options through the ICA. It seems only right to support the organization that has always been there for me!

What have been some of the most memorable moments or milestones in your experience with IC/BPS that have motivated you to support our cause for so long?

Some of my most memorable moments in my experience with IC/PBS were leading a workshop at the 2000 convention in Minneapolis (Living Well with IC), having an article by the same title published in "Family Urology", representing the ICA at a Chronic Pain seminar with ICA founder, Vicki Ratner, M.D., participating in an invitation only workshop with IC Pain Management Specialist, Daniel Brookoff, M.D., attending the ICA reception for donors at the annual AUA meeting in San Francisco and writing my own successful case for Social Security Disability.

How has your personal journey with IC/BPS shaped your understanding of the challenges faced by individuals living with this condition, and how has it influenced your involvement with our nonprofit?

My personal journey with IC/BPS has made me acutely aware of the challenges faced by individuals living with this condition and led me to understand the importance of maintaining a positive outlook and cultivating a strong support system.

In what ways do you believe our organization has made a difference in the lives of those affected by IC/BPS, and how has your long-term commitment helped contribute to our impact?

I believe that the ICA has made a difference in the lives of patients by providing education, support, and advocacy at the governmental level. I would like to think that my hands-on efforts in the early years as well as my long-term financial contributions have helped to contribute to the ongoing impact of the organization.

How do you envision the future of our organization and its role in supporting individuals with IC/BPS, and how can donors like yourself help us achieve our goals?

I think the ICA is on the right path to meet patients' needs. Online webinars are clearly the most cost-effective way to reach the greatest number of people. The monthly donor program provides an ongoing and predictable revenue stream and allows for future planning. It is also an easy way for patients to manage their giving.

What message would you like to share with potential donors about the importance of supporting our cause and the impact their contributions can make in the lives of those affected by IC/BPS?

It is important to give financial support to the ICA as it is always evolving to remain the premiere resource for not only patients and caregivers, but for the medical community, as well. Donations are a vital part of what allows the ICA to continue its mission.

Looking back on your 40 years of involvement with our nonprofit, what are you most proud of in terms of the progress we have made in raising awareness and providing support for individuals with IC/BPS?

I am most proud of the way the ICA has adapted to continue to best serve its patient population. Although I do miss the personal interactions with other patients at support group meetings and conventions, I can appreciate that they are no longer cost effective.

How has your personal journey with IC/BPS and your involvement with our nonprofit inspired hope and resilience in others facing similar challenges, and what message of encouragement would you like to convey to our supporters?

The ICA has served me as a vital resource throughout my IC/PBS journey. Knowledge is power and I believe that my understanding of my condition has afforded me the opportunity to "live well with IC" for more than 30 years.

As we strive to expand our reach and impact in the years to come, how do you see your continued support and the generosity of donors helping us advance our mission of improving the lives of individuals living with IC/BPS?

The need for financial support in the form of donations has been and will continue to be vital to the organization's continued success in advancing its mission.



Carol's Story

After five years of ongoing “bladder infections,” I came across a magazine article about IC in 1992. After reading that article, I made dozens of phone calls to find a urologist who was familiar with my condition. I found a urologist nearby who had treated just one other IC patient.

My IC was managed with DMSO instillations for about two and a half years. By that point, I was aware of the ICA and learned about an IC specialist and ICA Medical Advisory Board member at Stanford, Dr. Christopher Payne, who treated me for five years.

During that time, I explored several different treatment options and participated in clinical trials on an ongoing basis. My symptoms of frequency and urgency improved; however, my pain did not. In March of 1999, I had my first appointment at the Stanford Pain Clinic. I was a pain clinic patient for nine months, undergoing numerous pain management procedures and protocols. In January of 2000, I was released to my primary care physician who continued to write my prescriptions and monitored my pain. In 2005, I flew to Denver, CO to meet with IC pain specialist, Daniel Brookoff for a second opinion. I saw him on two separate occasions, and he advised that I continue with my prescribed pain management protocol. In the last 23 years, I have managed to do so with the help of a total of three primary care physicians.

My symptoms have consistently been frequency, urgency, and pain. Over time, I developed secondary conditions of fibromyalgia, chronic fatigue syndrome and irritable bowel syndrome.

As mentioned, I self-diagnosed and then found physicians to confirm. The first physician was a urogynecologist and the second a urologist.

After an additional 20 years, I continue to live well with IC.

The most important thing I would like to share is how critical it is to maintain a positive outlook and attitude. I became an advocate for myself and took charge of my condition, so I felt I had at least some control. I was also blessed with a strong support system from my husband, family, and friends.



Quote from my husband Richard of 40 years:

“The most difficult thing for me was seeing Carol continue to struggle with managing her symptoms and the resulting limitations, especially the need to self-catheterize. She always maintained a positive attitude and kept going. Together, we have been able make the necessary adjustments to enjoy our time together, as well as that with our family and friends.”