

The Interstitial Cystitis Association of America: lessons learned over the past 30 years

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Abstract: In 1984, interstitial cystitis (IC) was considered a rare psychosomatic disorder in post-menopausal women. In 2014, the Interstitial Cystitis Association of America (ICA) celebrated its 30th anniversary. We've come a long way since 1984 and great progress has been made. IC is now recognized as a condition that afflicts both men and women of all ages, including children and teenagers. It is not a psychiatric disorder. Though it was once thought to be an orphan disease (defined as affecting less than 200,000 people), we now know that there are millions of women and men who suffer from IC/BPS (bladder pain syndrome). In looking back over this period, there were seven key reasons why the ICA became so successful: an extremely dedicated ICA staff, Board of Directors and volunteers; a very strong Medical Advisory Board and participation of many other urologists from across the country and around the world; cooperation of the media; epidemiological studies; the ICA's Pilot Research Program; our representation in Congress; and a strong working partnership with the National Institutes of Health (NIH). Our history may prove useful to other advocacy groups.

Keywords: Interstitial cystitis/bladder pain syndrome (IC/BPS); bladder pain syndrome; Interstitial Cystitis Association of America (ICA); Interstitial Cystitis Association of America Advocacy Group; Interstitial Cystitis Association of America (ICA)-reasons for success

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The beginning

In 1983, as a third year medical student, I came down with severe suprapubic pressure, urinary urgency, frequency and burning pain in my bladder. The pain felt like a lit match in my urethra. I was barely able to function, and found it almost impossible to concentrate. I assumed I had a UTI, but a complete work-up was negative and antibiotics failed to reduce the symptoms. In search of a diagnosis and relief from the severity of the symptoms, I sought help from one urologist after another. Many told me that the tests were negative, and that there was nothing they could do for me. Others suggested that I was not cut out to be a doctor and that I should drop out of medical school, get married, and settle down into a more traditional lifestyle. I spent the last 2 years of medical school in intense, unremitting pain and

in isolation, imagining that I was the only one in the world with this disease.

Ultimately I made the diagnosis myself. While researching the problem in my medical school library (using Index Medicus at that time), I came across a footnote. It was almost 11 PM, I was exhausted and ready to quit, the library was about to close. With little energy left after 2 days of searching, I pushed myself to stay, and to my amazement, the footnote led me to an article that described my case exactly. It was entitled "Early Interstitial Cystitis", published in 1978 by Ed Messing and Thomas Stamey, both from Stanford University Medical Center (1). I was told by the urologist at my medical center not to 'hang my hat' on just one article. It's a good thing I did.

Since my bladder looked normal during a routine cystoscopic procedure in the office, it took many months of

convincing the urologist at my medical center to consider a cystoscopy under general anesthesia. The procedure was eventually done, according to the recommendations in the article I had found. The diagnosis was finally made based on numerous glomerulations seen on second distention of the bladder (I realize that this does not necessarily meet today's criteria, but back in 1984 it did). For me, it was an enormous relief just to know that there was a name to what I was suffering from, but the description in *Campbell's Urology* suggested interstitial cystitis (IC) was a post-menopausal disease, and I was only 33 years old. It also suggested that IC was rare—but was it? There was only one way to find out—to take my story to the media.

The media

In 1985, I was an orthopedic surgery resident in New York City. One of my closest friends had just interviewed for a job at a public relations firm. She told the people there about IC and my story. One publicist was particularly interested, and I followed up with a phone call to her. She contacted a producer at *ABC's Good Morning America*. This led to an interview on their show. Phil Hanno, M.D., a urologist from the University of Pennsylvania, was kind enough to join me, and a 5-minute interview led to an extraordinary response. An Interstitial Cystitis Association of America (ICA) volunteer had rented a small P.O. Box at the local post office, hoping that we'd at least receive a few letters after the interview, and at first no letters arrived. I was extremely disappointed. A week later, however, this volunteer received a call from the post office telling her that the ICA had received six large mail bags of letters and that she needed to come retrieve them right away. We had received over 10,000 letters within one week, just from a 5-minute interview on TV where we explained what IC was, its symptoms and where to find help. There was such a large response at *Good Morning America* that Dr. Hanno and I were asked back for a second interview 6 months later. Of course, not all of those who wrote to the ICA had IC, but many did, or knew someone who likely had the condition. In the original letters we received, people poured their hearts out to us. Letters from women in their 70s who had suffered with IC for a majority of their lives without any help were particularly poignant.

Below are samples of the types of letters we received:

"I am a nurse and I have interstitial cystitis. It took over 15 doctors and over 2&1/2 years to even get a diagnosis. I read the article in

the paper (about the ICA) and felt the need to respond right away. Needless to say 14 doctors didn't believe me and recommended psychiatric care. I knew something was wrong and persisted. I haven't been able to work for 2 years. I am told I have to learn to live in pain without medication. I wish it were possible to put some doctors in my body so they could feel what it is like to have this pain. I have constant, intense unrelenting, deep pain, and hard as I try mentally, physically and emotionally, I cannot stand it for long without relief. I feel like I'm being tortured without respite. It makes your life an endurance contest."

"As you know, 6 years is a long time to put up with this terrible condition. I am almost at the end of my rope. Thoughts of suicide intrude in my mind very frequently....I do not want to sound like a whiner but I think you will understand. IC has taken practically all the good things out of my life....This condition has caused all kinds of trouble between me and my wife. I am kind of useless now. Anyhow, thanks for your info and kindness.... Just think how astronomical the odds of a man getting IC are."

Two years later, in 1987, the following letter was syndicated nationwide.

"Dear Ann Landers:

After 3 years of non-stop pain, 40-60 bathroom trips a day, little sleep, lots of tests, 12 doctors, hundreds of allergy shots, diets, antibiotics, and six unnecessary operations, I have finally been diagnosed as having interstitial cystitis, a 'rare' disease that doctors seldom look for and may turn out to be not so rare...."

The typical history was urinary urgency, frequency and bladder pain over a span of many years. Patients had often seen five to ten physicians, had had complete work-ups that were negative, and had received no diagnosis. They were told that either nothing was wrong or the symptoms were "all in their head". These IC patients were suffering from terrible pain and urinary frequency as often as every 10 minutes. They were trapped in their own home, cut off from their friends, family and society in general, due to their severe disability. On occasion, even family and friends began to believe that the symptoms were not real since the doctor had said so.

It became clear that IC was not a rare disorder and that there was an urgent need to address the issue. I started the ICA in the living room of my NYC apartment in 1984. We were a small group of volunteers with an overwhelming amount of work to be done. I chose the brightest sounding women who contacted us from NYC and across the country after the *Good Morning America* interview, and we gradually added additional volunteers.

We could not afford to hire a public relations firm,

so I personally pounded the pavement for many years trying to get media coverage. At first, there were many rejections. ‘Not relevant for our audience’ was a typical response. But eventually, through networking, contacts and sheer perseverance, we were able to get coverage by Jane Brody of *The New York Times*, *The LA Times*, *U.S. News and World Report*, *NPR (National Public Radio)*, *CNN*, *The Philadelphia Inquirer*, *The Chicago Daily Tribune*, *The Boston Globe*, *Associated Press*, as well as almost all of the national women’s magazines including *Ms. Magazine*, *Glamour*, *Working Woman*, *Redbook*, *Cosmopolitan*, *Mademoiselle*, *Self*, *Good Housekeeping*, *Woman’s Day*, *Ladies Home Journal*, *Family Circle*, *Prevention*, *Consumer Reports*, *Weight Watchers Magazine*, and many others. *Good Housekeeping*, *Self*, *Woman’s Day*, and *Cosmopolitan* featured IC and the ICA on multiple occasions.

The media was a critical component in the formation of the ICA. It was clear from the beginning that the media would be key to finding patients with IC, to increasing awareness among physicians and the public, and most importantly, legitimizing the disease. Once a story on IC was in print or a segment was aired on TV, patients identified themselves and were able to go to their doctors armed with information, and doctors were more likely to believe them.

Both physicians and patients were educated by the media. Early on, the ICA began producing an excellent quarterly newsletter and brochures on key topics for patients and a separate newsletter for physicians. This kept them informed about the latest theories, research and treatments. Scientific journal articles soon followed.

Fortunately, fax and cell phones became available in the mid 1980’s, followed by email and the Internet. This enabled the ICA to centralize communications, and allowed patients and physicians access to an enormous amount of information available on the ICA’s website, www.ichelp.org.

We have all learned a great deal since 1984. Below are a few of the highlights:

- IC/bladder pain syndrome (BPS) can affect both men and women of all ages, including children and teenagers;
- It is not a psychosomatic disorder. In *Campbell’s Urology (1978–1985)*, IC was included in the chapter entitled Psychosomatic Conditions in Urology. “*Interstitial Cystitis may present the end stage in a bladder that has been made irritable by emotional disturbance.... a pathway for the discharge of unconscious hatreds.*” (2). This was permanently omitted in the following edition

published in 1986;

- IC is often accompanied by other medical conditions such as IBS, chronic fatigue syndrome, vulvodynia (which did not have a name back in 1985), and endometriosis (3);
- Researchers have found no evidence to date that IC/PBS is caused by an infection;
- The average age of onset of this condition is 32–34 years old;
- There is a genetic component to this disease;
- Elmiron became the first FDA approved oral medication for use in IC in 1996. Techniques in pelvic floor therapy have advanced and are much more effective as a treatment;
- Techniques in pelvic floor therapy have advanced and are much more effective as a treatment;
- Dietary modifications are now better understood and play an increasingly important role;
- Epidemiology—see section on epidemiology.

Despite great progress, it still takes some patients many years to obtain a diagnosis, only to find that no therapy available helps ease their symptoms.

“Enclosed are three donations made in memory of my wife, Joanna...The extreme pain and despair over chances for a cure caused her to end her life on April 8th. We hope that these donations help in some small way to find a cure and save others from this fate.” (44 y/o female survived by her husband and teenage son).

“I am an attorney for the Personal Representative of the estate of _____, and am writing to inform you of (her death).” (43 y/o female who committed suicide due to IC, and donated funds to the ICA).

“I read the letter my mother left me. She was so sad to go, in fact did not want to go, but she could see no other way. Part of the problem was that she was 65, and had undiagnosed IC for almost 20 years, but diagnosed just 4 years ago. What was frustrating to us was watching her go to doctor after doctor with little relief. She wasn’t depressed or mentally ill at the time she made her decision... Next to her bed was “The Final Exit by Derek Humphrey.” While the doctors failed her, Mr. Humphrey gave my mother a way to end the pain easily, effectively, and quickly. It was a relief to learn that she did not suffer and it did not take long... but what a sad end to a vibrant woman’s life. She was so very young for her age and it pains me to think of what IC took from her...” (survived by two daughters and two grandchildren).

Although there is no data available on IC and suicide, IC can be a painful, incapacitating disease that must

be diagnosed early and treated aggressively, with pain medication if necessary, to avoid this outcome.

The origins of the ICA's Medical Advisory Board

To our amazement, the very first urologist to contact the ICA did so before any TV stories aired or print media was published. Grannum Sant, M.D., from Tuft's University Medical Center, and the editor of this journal, sent a cover letter along with his CV, offering to help us in any way that he could. We were thrilled. Shortly afterwards, Phil Hanno, M.D., from University of Pennsylvania also contacted us, and based on a patient's recommendation, came to meet with me in New York City, bringing two of his researchers. Many excellent ideas were generated from that meeting, and I was enormously grateful. Two weeks after this meeting, our interview on *ABC's Good Morning America* aired live with both Dr. Hanno and me, and the ICA was off and running. Alan Wein, M.D., Chairman of Urology at University of Pennsylvania, was instrumental in moving our cause forward and opening many doors for us. In the beginning, since my field was orthopedic surgery and the focus on IC was so new, it would have been impossible for me to get an article published in a urology journal. So I submitted an editorial I had written to Dr. Wein, who added a brilliant introduction and conclusion, and wedged my editorial in the middle, without my name, entitled "Tell Her to Get a Urine Culture, Take Some of That Medicine I Prescribed a While Ago, and Call Me in a Few Days", published in *Neurourology and Urodynamics*, 1985 (4). That one article opened the door for me to publish in urology journals, with the support and assistance of both Dr. Wein and Dr. Hanno.

Other urologists who joined our cause early on included Kristene Whitmore (University of Pennsylvania, USA), Rob Moldwin (Long Island Jewish Hospital, USA) Christopher Payne (Stanford University Medical Center, USA), and Lowell Parsons and colleagues at UC San Diego, the only group in the U.S. to my knowledge who were researching IC before the ICA was formed. The ICA's Medical Advisory Board grew from there. Currently, the ICA has an extensive referral list and outstanding urologists on its Medical Advisory Board that include specialists from other fields such as ob-gyn and pain management.

"The ICA was and still is the only nonprofit health association in the United States solely dedicated to improving the quality of healthcare and lives of people

living with IC. It provides advocacy, research funding, and education to ensure early diagnosis and optimal care with dignity for people affected by IC." (ICA mission).

Over time, having heard about the ICA in the United States, IC organizations began to form in other countries. These countries included Germany, the Netherlands, Italy, Japan, and England among others. Now there are over 27 organizations and/or support groups established around the world. Patients reached out to urologists in their respective countries, and conferences on IC were held. This ultimately led to the formation of ESSIC (International Society for the Study of BPS/IC), which meets in a different country each year.

The ICA's Medical Advisory Board

Our Medical Advisory Board was extraordinarily dedicated to promoting research and treating patients with IC. Having a strong MAB was critical for many reasons. A handful of well reputed physicians enabled us to gain access to and be included in many meetings and conferences that would not have been possible on our own. These physicians were willing to partner with us and include us in many activities. The ICA was introduced to leaders at the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), which also included urology and hematology. We worked together with the Director of Urology to plan biannual scientific conferences on IC, in addition to holding an ICA patient meeting at the same time. There was no substitute for in-person interaction. IC patients meeting other IC patients, as well as urologists well known in the field of IC research built a tremendous amount of good will and trust.

The ICA was included in many other urological and associated organizations such as the American Urological Association (AUA), The Society for Women's Health Research, The American Urogynecological Society, The American Congress of Obstetrics and Gynecologists, The National Association for Continence, the International Association on Incontinence, the AUA IC Guidelines Committee, The International Association for the Study of Pain (IASP) and its subcommittee Pain of Urogenital Origin (PUGO), Society for Women in Urology (SWIU), Society of Urologic Nurses and Associates, and The International Society for the Study of BPS/IC (ESSIC).

The ICA was included at the annual AUA meetings. At these meetings, the ICA set up a booth at the AUA exhibit hall. At the outset, there appeared to be a complete lack

of interest among urologists. They used to stop by our booth in the exhibit hall and snicker at us as they helped themselves to all of our sample pens, telling us that IC did not even exist. Over time, physicians came to our booth wanting to know the latest in IC research and any new treatments that became available that year. However, this did not happen quickly. It took many years and tremendous persistence to find urologists, urogynecologists, gynecologists, pain specialists, and physicians who treated IC related diseases from across the country who were interested and willing to treat IC patients. We always had a one page 'cheat sheet' with the latest information prepared for them. This was the most popular item at our booth.

At the AUA, IC was introduced slowly. First came poster sessions, followed by moderated poster sessions, plenary sessions and IC courses over time. This represented great progress. In addition, articles on IC were increasingly included in *Urology*, *Journal of Urology* and other prestigious journals; supplements to these journals were devoted exclusively to IC, as were books and monographs. *Urology Times* published numerous articles on IC. In 1999, for the first time, IC was included in the standard review course for urology residents who planned on taking their urology boards.

Epidemiology

How did we prove that a large number of people have IC and that it was not a rare disease? Epidemiology was the answer. Historically, IC was considered to be a rare post-menopausal condition in elderly women, with perhaps 45,000 estimated cases. The very first *Epidemiology Study* conducted on IC in the United States was published in 1988 by Dr. Philip Held and his team at the Urban Institute. NIDDK also provided some support.

Critical to legitimizing the disease, Dr. Held and his team found that:

- (I) For every one patient diagnosed with IC in the urologist's office, five went undiagnosed;
- (II) It took an average of 4.5 years and five doctors to achieve a correct diagnosis;
- (III) IC patients scored worse than patients undergoing renal dialysis on 'Quality of Life' questionnaires;
- (IV) A total of 60% of patients reported pain with sexual intercourse, many so severe that they abstained altogether;
- (V) By combining medical expenses incurred by an IC patient with lost wages because of disability, Held's

study calculated the economic impact of the disease to be as high as \$1.7 billion per year.

Since that time, several epidemiological studies have been published. The Rand Corporation *Interstitial Cystitis Epidemiology study* (RICE study) by Sandra Berry *et al.*, published in 2011, estimated that 3.3-7.9 million women in the U.S. have IC/PBS. The authors believe, however, that this is a substantial underestimation. "Symptom severity and impact were comparable to those of adult women with established diagnoses. However, only 9.7% of the women reported being assigned a BPS/IC diagnosis." Berry *et al.* estimated that 2.7% to 6.5% of women in the United States have urinary symptoms consistent with a diagnosis of IC/BPS (5). Konkle *et al.* concluded that (The Rand study) "strengthen(s) the existing body of evidence which suggests that this condition is substantially burdensome, and likely underdiagnosed and undertreated in the United States." (6).

Clemens *et al.* evaluated data from the BACH study (Boston Area Community Health Survey) published in 2007, and concluded that between one and four million men have IC in the U.S. (7), which is much higher than previously thought.

There is now no way to dispute that IC/BPS exists, with so much data to back up the numbers. These epidemiological studies confirm that there are many more men and women who have IC/BPS in the U.S. than previously thought. Although there are many more women than men who suffer from this condition, the original ratio of 9:1/female to male in the older literature may be overstated.

Advocacy: Congress and NIDDK

Congressional Report Language and the Health and Human Services Committee

We learned a tremendous amount from other organizations, especially from Abbey Meyers, Founder and President of the "The National Organization for Rare Disorders". Meyers recommended that that we attend public hearings held on Capitol Hill each year. She pointed out that it was not only imperative to appear and give testimony, it was even more important to submit the testimony, since some of it was placed in the annual Congressional Report Language. This annual report explicitly stated to the National Institutes of Health (NIH) (NIDDK in our case) how the budget Congress allocated to them should be spent.

The first year, IC was only mentioned in a few sentences

with a recommendation to begin studying IC. Funds were specifically allocated for IC research, yet somehow they got ‘accidentally’ directed to prostate research. We learned quickly, and that never happened again. Each year, a little more about IC research was added to The Congressional Report, until we had over one-half page of coverage that stipulated what IC specific research we wanted to see undertaken.

We learned that during a Republican administration, few specific criteria were given to NIDDK on how funding should be allocated towards IC as well as other urologic conditions. Congress did not want to ‘micromanage’ NIH’s budget and often recommended broad commitments for basic bladder research, which often worked to our disadvantage. However, during a Democratic administration, we could count on Congressional and NIDDK support for IC specific projects.

This was immeasurably helpful to know because many times during a Republican administration, despite funding specified for IC in Report Language, the Director of NIDDK decided that the funds could be used for basic, general research on the normal bladder. Although such research was essential, the ICA wanted the funds to also cover specific areas for IC that we knew were important to finding a cause of IC, thus moving us closer to a cure. Many political battles ensued during these times.

Meyers also discussed the importance of the Health and Human Services Committee with us. She emphasized the importance of visiting each committee member every time that we were in Washington D.C. in order to update them on the progress being made and to ask them to support various projects, write a letter on our behalf, etc. We had a lobbying week in the spring of each year and visited as many congresspersons as we could from the various states that patients represented.

Phyllis Greenberger, CEO of the Society for Women’s Health Research, provided many opportunities for us. One of her contributions was making sure that the ICA was always included in special Congressional hearings, conferences on women’s health, and in all of the society’s annual conferences as well.

Several of the ICA staff and Board met with Harry Reid (D), Senator from Nevada, very early on, and he took an interest in our story. This was long before he was the Majority Leader of the Senate. He has been our backbone of support since the beginning, and we are indeed sad to hear that he will be retiring when his term is up in 2 years. At that time, we were also able to hire a lobbyist who was phenomenal and who gathered a great deal of support on the Hill, both

Democrat and Republican.

We once had a dramatic standoff in Senator Reid’s office. The Director of NIDDK at the time wanted all the IC allocated funding in Congressional Report Language to go towards basic bladder research, with no funding going specifically to IC. A meeting was called by Senator Reid, and the Director of NIDDK arrived with an entourage of approximately 10-15 people at Senator Reid’s office. I arrived with two people. Senator Reid asked the Director of NIDDK to explain his position, and then asked me to explain mine. I used the example of HIV/AIDS—that you could study the basic immune system for years, but if you didn’t study the HIV virus at the same time, you would not come any closer to finding the cause or cure of HIV/AIDS. Senator Reid stood up, not wanting to waste time, and said to the Director of NIDDK, “We can do this nicely or not” and proceeded to walk out of the room. This inferred that he planned to support IC specific research, as was dictated by Congressional Report Language that year. The three of us (myself and two others) were elated, having won a major battle. Many IC specific proposals were funded by NIDDK that year.

The ICA was and is extremely grateful to the Director of Urology at NIDDK during these many years including Lee Nyberg, M.D., Ph.D., now retired, and currently Dr. Chris Mullins, Ph.D., for their tremendous support, and for allowing the ICA to actively participate in all biannual national IC scientific conferences, clinical trials meetings, the Rand study, and to have a voice at other national and international meetings. I was appointed to serve on the NIDDK Advisory Council for a 4-year term. This council is responsible for reviewing all final grants recommended for approval as well as making a final decision on those grants that scored just above the critical number of points needed for approval. (The lower the number, the better the score). It was quite an honor, and it gave the ICA a voice when urologists were making decisions about whether or not to fund various urological grants.

Pilot research program through the ICA

This program began very early on in the formation of the ICA, thanks to the generous donation of one of the ICA’s Board Members. Subsequently, the ICA raised research funds each year and was able to raise enough money annually to fund three to four projects of approximately \$10-15,000 each. We were very fortunate to have a benefactor, The Fishbein Family IC Research Foundation,

who donated a substantial amount of research funding each year to the ICA. Their twin daughters both have IC. Every year, a Request for Applications was sent out by the ICA specifying what areas of research we were interested in pursuing. The grants were then reviewed by committee, including the ICA President and several of the ICA's Medical Advisory Board Members, a combination of researchers and clinicians. Once the recipients were chosen, they produced preliminary data that would at least give them a chance of competing for an NIDDK grant. Without any preliminary data, there would be little if any chance of being successful. This critical program was a steppingstone to NIDDK funding. We had an exceptionally high rate of ICA funded grants that went on to receive funding by the NIDDK—over 40%.

The staff

Staff is the backbone of any organization. I consider myself fortunate to have worked with so many talented and gifted staff, Board Members and volunteers. They did the work that needed to be done, and if it took 7 days a week, they put in the time. We ran on a shoestring budget, and often could not afford an office. The pay was hardly commensurate with what they deserved, but they persevered. Many of us lived in different areas of the country, and those of us who had IC often worked from home.

The ICA staff had numerous responsibilities: responding to phone calls and answering the mail (literally thousands of letters and calls in the course of a year); working with NIDDK on biannual co-sponsored national conferences, both scientific and patient-oriented; working with The Centers For Disease Control; congressional lobbying; running the annual ICA pilot research program; working with the media; arranging for regional patient conferences; fundraising; grant writing; working with pharmaceutical companies; keeping an updated physician registry; running weekly staff meetings, writing quarterly newsletters for both patients and physicians; attending the AUA and other related annual meetings plus dozens upon dozens of other tasks. Given the severity of the pain, few were as motivated or as effective as were the staff, board members and volunteers with IC (and several without IC) in gaining a voice in the scientific and political community.

Conclusions

With talent, perseverance, determination and a great staff, the ICA, grew into an extraordinarily successful

organization. It was an uphill battle, but the ICA put IC 'on the map'. Patients learned from each other, reached out to urologists and other specialists, and increased awareness among these physicians. We developed a superb ICA Medical Advisory Board, insisted on epidemiological studies, began a pilot research program of our own, and worked closely with both Congress and NIDDK. Our history may provide a useful blueprint for the development of future medical nonprofit organizations.

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Dedication: This paper is dedicated to the many outstanding ICA staff, board members, volunteers, medical advisory board members, and to the many IC patients and urologists and other specialists worldwide, both past and present, who have worked with the ICA over many years. It is also dedicated to the millions of patients with IC/BPS who have endured an immeasurable amount of suffering, and to those who, unable to endure such immense suffering, found suicide as the only way out. And finally, this paper is also dedicated to Daniel Brookoff, M.D., (now deceased) who was one of the finest, most compassionate and extraordinary physicians I have ever known.

Footnote

Conflicts of Interest: The author has no conflicts of interest to declare.

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