

Profile of Jill Osborne: IC Network

"There is nothing so moving, not even acts of love or hate, as the discovery that one is not alone." Jill Osborne, Interstitial Cystitis (IC) patient and founder of the IC Network, believes in this quote by Robert Ardrey and lives by it everyday. She strives to reach all IC patients and let them know they are not alone.

Osborne's struggle with Interstitial Cystitis inspired her to start the IC Network in 1995. Although Jill has finally reached a very good place in her life, her journey with IC and her desire to help others cope with IC has not been an easy one. Her IC symptoms first began when she was 13 and she spent three years struggling with frequency and urgency to the point where sitting through classes in school was almost impossible. She endured dozens of urethral dilatations which was the treatment of choice at that time. Though her bladder symptoms improved by the time she finished high school much of her 20s was spent in the doctors office trying to understand the wide variety of related conditions that she progressively developed including vulvodynia, irritable bowel, allergies, food sensitivities and Sjogren's Syndrome. Her IC returned at the age of 32, with severe debilitating pain. After being unable to live her life like an 'average' person, Osborne finally received a diagnosis from her doctor: Interstitial Cystitis. At first, Osborne experienced relief from her diagnosis; she finally knew what plagued her. "I was so relieved," she said.

"I always knew that my pain was real, but to finally have a name for my condition was a relieving confirmation. I was finally able to educate myself about IC and find other people to talk with who have IC."

However, her relief disappeared almost immediately when her doctor told her she would have to rely on disability services for the rest of her life. One of the many doctors she saw told her "you will always be a burden to your family." "I was furious that someone could say that to me," she noted. "I had a degree in Pharmacology, had gone to graduate school, received a masters degree in Psychology, was awarded the Presidential Management Fellowship from the White House and I wanted to continue my education to receive my PhD. IC was putting my life on hold." Osborne's anger fueled a determination that allowed her to take a stand and help others who felt her same desperation and frustration.

To help overcome her feelings of sadness and isolation, Osborne started a Northern California IC group and enthusiastically dove into the IC literature. This literature gave her a new perspective on the disease as well as diet tips to help relieve flares. It was the first time she learned of diet's role in



managing IC. Osborne realized that she could not be the only one who was confused and frustrated by the disease and her lack of knowledge about it. She knew that people needed to talk to others who could understand the pain.

In 1994, she found a way to join together not only those who were too ill to attend her local support group, but also those suffering around the world. "There were people at home, suffering in silence, like me. I knew I needed to do something." The rise of America Online (AOL) helped her to fulfill that need. She created a cyber-support group dedicated to educating patients via a message board. The added element of a support chatroom brought men and women together to discuss the disease, while giving them the comfort of anonymity to speak about the effects beyond the physical pain, such as difficulties with intimate relationships.

The following year, the IC Network was born. It was the first website dedicated to Interstitial Cystitis. Osborne's fundamental goal of the project was to provide free, high quality information to IC patients. She stresses that in addition to education, support is absolutely necessary for those struggling with IC. She recalls an episode where simply a helping hand saved her life. "On July 4, 1993, I considered taking my life because of the pain. I simply could not sit, stand or lie down. All I could do was pace. If I had had a method, I really might have done it. The agony was unbearable. What I did have, though, was a hand to grab onto from my support group. It got me through. That's what I want the IC Network to do. I want it to be that hand extended in love, friendship, and hope."

Today, the site is doing just that. It serves over 200,000 patients per month free of charge. The network expanded its operations by incorporating diet tips, options for low-income sufferers, and directions to support groups and networking sites along with information about clinical research trials being conducted.

The website displays vast amounts of information for those suffering with IC. Osborne has done the majority of the research for the site on her own. She reads and studies monthly journals in order to gain new insight into the disease and reinforce already acquired knowledge. She gains much of her information from doctors and urologists, which she then passes on to the site's followers.

"I hope that the IC Network can build a sense of compassion towards patients who for many years have suffered in silence at home alone. They deserve compassionate care not only from the medical community but from their families as well."

While Osborne is extremely pleased with the direction in which the IC Network is heading, she does have long term goals in mind. Education has long been one of the fundamental values of the IC Network, and Osborne would like to continue to see effective results from their efforts. Her research has shown that many adults are more capable of learning and understanding information by watching a video, rather than reading text. Because of this, the IC Network introduced educational videos in 2009 that are currently on YouTube (an internet search engine accessible in many countries, exclusively for watching videos about any topic) and receiving rave reviews. Earlier this year she also began the web based Bladder Academy, a series of live video lectures and classes. Osborne is passionate about reaching out to young patients as well. In an effort to relieve their anxiety, Osborne and her team are hoping to publish a book directed specifically at IC youth patients.



Osborne is optimistic that her educational tactics will further help patients in their daily lives. Many patients, Osborne included, have experienced injustices in the workplace because of their IC. She has found that too many people do not believe in nor do they understand the severity of the pain.

While working as a public relations / marketing director for a national non-profit organisation, Osborne's superior told her that she did not believe that she was in any pain. She was convinced that Osborne simply did not want to come to the office and suggested that "she came from weak stock." Even after Osborne was hospitalised a short time later, her boss did not believe that she was truly ill, because Osborne "did not look sick." Osborne thinks it is crucial for patients to understand their rights as workers. She urges IC Network followers to understand their personnel policies and encourages them to find out about the disability acts that protect them as employees.

She hopes that education can help others cope in the work environment. She describes the story of a member of the IC Network who was embarrassed and degraded by her employers. This particular woman informed her boss that, because of her condition, she would need to use the restroom every 30 minutes. Her boss was not pleased by this and told the woman she could not visit the restroom so frequently. Instead, he told her to wear an adult diaper and to urinate into the diaper while operating the cash register. She complied because she did not know her rights. Osborne is attempting to help people like this woman learn their rights and prevent humiliating situations. Aside from education, another thing Osborne believes that is lacking in the treatment of IC patients is the treatment of pain. Though many preventative tips are provided, she feels pain management is often neglected. Her response when asked about the Pfizer BLAZE Study, she exclaimed, "I think it's fantastic!" Osborne is even helping to spread the word about the study to the IC Network community by posting study information on the ICN website, Facebook and Twitter pages, and including study information in an email blast and patient newsletter.

"I want to remind IC patients that they are still important members of the community who, I hope, will help other patients who are struggling."

Osborne quotes Maya Angelou, the American autobiographer and poet, when speaking of clinical trials: "When we cast our bread upon the waters, we can presume that someone downstream whose face we may never see will benefit from our action, even as we enjoy the gifts sent to us from a donor upstream." Osborne explains, "This quote absolutely speaks to clinical trials. Because clinical trials are a process, even the failures are vital information for us. They tell us the direction we have taken before is not the correct one and that allows us to continue to strive for a solution that works."

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Osborne is thankful for the doctors who conduct clinical research trials, especially those diagnosing and treating Interstitial Cystitis. She has a message for these doctors: "Thank you for believing us and taking us seriously. Thank you for holding our hands because we are scared and confused. Thank you for the articles that you write to educate us so that we can better understand and tolerate our disease. Thank you for being compassionate."

Perhaps Osborne should also be thanked for her efforts and dedication. But Jill Osborne is not looking for gratitude. She just wants to continue to help. She says she truly and genuinely wants to help with any IC research being conducted. Osborne says she frequently collaborates with researchers and research teams working within the IC movement. "I am a researcher at heart and had hoped to complete a PhD when my IC began. Unfortunately, sitting in a car or the classroom was excruciating at the time. I have a strong appreciation for the research community and love to support their work."

"The ICN offers clinical trial recruitment. We get a superb response from patients who want to participate. We also provide research survey development and real time data analysis for a variety of studies including sexuality, pain, food and others."

"Data collected on our site has been presented at major IC and urology conferences including NIDDK Bladder Science Symposium, AUA, ISSWSH and others. We've also assisted a number of graduate students developing data for their doctoral dissertations."

"I have not met an IC patient that I did not make a connection with. The thing is, we can look into each other's eyes and have a common bond. It's that sense of suffering that unites us in our quest for wanting to get better."

To those suffering from IC, Jill Osborne sends her message; "We are here and we care. We sincerely want to help. I believe in the IC Network's motto, 'There is nothing so moving, not even acts of love or hate, as the discovery that one is not alone.' To be alone and in pain is terrifying, frightening, and exhausting. But when you realize that there is a hand next to you and that someone can help you, the load becomes lighter. You are not alone."

SITE PORTRAIT: DR. TOMOHIRO UEDA

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He sees about 100 patients a day and performs 3-5 operations a week. Despite this demanding workload, he manages to inform his patients fully about the study and its requirements while addressing any concerns they may have. Dr. Ueda says the most commonly expressed concern is about the side effects of the drug. He has found that after explaining any possible complications, patients are usually happy to participate. "Most IC patients have been affected by the disease for quite some time, but they have not been extensively evaluated before they come to us," he says. Because these patients have not been treated for their IC before, they are more willing to participate in the study despite any apprehensions they may have. Like the study site thousands of kilometres away in California, Dr. Ueda also finds that speaking with patients about their concerns on an ongoing basis makes them more likely to remain interested in the trial.

Dr. Ueda has dedicated the majority of his time to helping improve the quality of life for those living with IC/PBS. After recognising patients' need for support as they struggled daily with IC, Dr. Ueda helped to establish the first Interstitial Cystitis support group in Japan, named "Tomo-no-ki". He also founded the non-profit organisation, Comfortable Urology Network (CUN) in 2005, which aims to eliminate uncomfortable urology issues nationwide. As a well respected leader in the IC community in Japan, Dr. Ueda is appreciated and well respected for his leadership role, and this in turn serves as a strong foundation from which to ensure the success of this important Pfizer clinical trial.

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