



Conquering IC.
Changing Lives.

STATEMENT OF
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REGARDING FISCAL YEAR 2011 APPROPRIATIONS FOR THE
DEPARTMENT OF DEFENSE

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SENATE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON DEFENSE

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Chairman Inouye, Ranking Member Cochran, and distinguished members of the Subcommittee, thank you for the opportunity to discuss Interstitial Cystitis (IC) and to share my story the Subcommittee. My name is Lauren Snyder, and I am a 29-year-old special needs teacher from Haddon Township, New Jersey. I am also a volunteer with the Interstitial Cystitis Association (ICA), the nation's foremost non-profit organization dedicated to improving the quality of life for people living with IC. The ICA provides advocacy, research funding, and education to ensure early diagnosis and optimal care with dignity for people affected by IC. Until the biomedical research community discovers a cure for IC, our primary goal remains the discovery of more efficient and effective treatments to help patients live with the disease.

IC is a chronic condition characterized by recurring pain, pressure, and discomfort in the bladder and pelvic region. The condition is often associated with urinary frequency and urgency, although this is not a universal symptom. The cause of IC is unknown. Diagnosis is made only after excluding other urinary and bladder conditions, possibly causing one or more years delay between onset of symptoms and treatment. Men suffering from IC are often misdiagnosed with bladder infections and chronic prostatitis. Women are frequently misdiagnosed with endometriosis, inflammatory bowel disease (IBD), irritable bowel syndrome (IBS), vulvodynia, and fibromyalgia, which commonly co-occur with IC. When health care providers are not properly educated about IC, patients may suffer for years before receiving an accurate diagnosis and appropriate treatment.

Although IC is considered a "women's disease", scientific evidence shows that all demographic groups are affected by IC. Women, men, and children of all ages, ethnicities, and socioeconomic backgrounds develop IC, although it is most commonly found in women. Recent prevalence data reports that 3 to 8 million American women and

one to 4 million American men suffer from IC. Using the most conservative estimates, at least one out of every 77 Americans suffer from IC, and further study may indicate prevalence rates as high as one out of every 28 people. Based on this information, IC affects more people than breast cancer, Alzheimer's diseases, and autism *combined*.

The effects of IC are pervasive and insidious, damaging work life and productivity, psychological well-being, personal relationships, and general health. Quality of life (QoL) studies have found that the impact of IC can equal the severity of rheumatoid arthritis and end-stage renal disease. Health-related QoL in women with IC is worse than in women with endometriosis, vulvodynia, or overactive bladder alone. IC patients have significantly more sleep dysfunction, higher rates of depression, increased catastrophizing, anxiety and sexual dysfunction.

After sustaining permanent damage to my gastrointestinal tract as the result of salmonella poisoning and developing pelvic floor dysfunction, I underwent a number of surgical procedures that revealed the extent of damage to my bladder. After other conditions were ruled out, I finally received the diagnosis of IC and was able to begin meaning and appropriate treatment. In addition to medications, I receive Botox injections into my pelvic floor, as well as bladder instillations. In my case, these treatments, as well as the multiple surgeries I have undergone, require general anesthesia, hospitalization, and extended recovery time, causing me to miss work and other activities. As a person living with a disability, my work with special needs children is particularly rewarding. Unfortunately, my job requires bending, lifting, and repositioning my students, which is painful and challenging with my IC symptoms. In addition to teaching, I am also a swimming coach, but I have had to reduce my hours as extended exposure to the chlorine in the pool aggravates my bladder.

Although IC research is currently conducted through a number of federal entities, including the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC), the DOD's Peer-Reviewed Medical Research Program (PRMRP) remains essential. The PRMRP is an indispensable resource for studying emerging areas in IC research, such as prevalence in men, the role of environmental conditions such as diet in development and diagnosis, barriers to treatment, and IC awareness within the medical military community. Specifically, IC education and awareness among military medical professionals takes on heightened importance, as the President's FY11 budget request does not include renewed funding for the CDC's IC Education and Awareness Program.

On behalf of the ICA, and as an IC patient, I would like to thank the Subcommittee for including IC as a condition eligible for study under the DOD's PRMRP in the fiscal year 2010 DOD Appropriations bill. The scientific community showed great interest in the program, responding to the initial grant announcement with an immense outpouring of proposals. We urge Congress to maintain IC's eligibility in the PRMRP in the fiscal year 2011 DOD Appropriations bill, as the number of current military members, family members, and veterans affected by IC increases alongside the general population.