Conquering IC.
Changing Lives.

STATEMENT OF
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INNOVATION HEARING – OUTSIDE WITNESS TESTIMONY

SUBMITTED TO
THE SENATE COMMITTEE ON APPROPRIATIONS

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Thank you for the opportunity to present the views of the Interstitial Cystitis Association (ICA) regarding the importance of federal investments in research. For fiscal year 2015 (FY15), ICA strongly supports a funding level of $32 billion for the National Institutes of Health (NIH) as well as $7.8 billion for the Centers for Disease Control and Prevention (CDC). CDC provides important infrastructure to disseminate research gains. Budget cuts have not only slowed the pace of innovation, but also jeopardized the public health infrastructure that puts hard-won innovations into practice.

ICA was founded in 1984 and remains the only nonprofit organization dedicated to improving the lives of those affected by IC. The Association provides an important avenue for advocacy, research, and education relating to this painful condition.

The effects of IC are pervasive and insidious, damaging work life, psychological well-being, personal relationships, and general health. Symptoms include recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region. It is often associated with urinary frequency and urgency. This condition may also be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP). It is estimated that as many as 12 million Americans have IC symptoms.

The exact cause of IC is unknown and there are few treatment options available. There is no diagnostic test for IC and diagnosis is made only after excluding other urinary/bladder conditions. It is not uncommon for patients to experience one or more years delay between the onset of symptoms and a diagnosis of IC. This is exacerbated when healthcare providers are not properly educated about IC and some patients suffer many years before they are diagnosed and empowered to attempt potential therapies.

RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

NIH maintains a robust research portfolio on IC with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) serving as the primary Institute for IC research. Research currently underway holds great promise to improving our understanding of IC and developing better treatments and a cure. The NIDDK Multidisciplinary Approach to the Study of

Chronic Pelvic Pain (MAPP) Research Network studies the underlying causes of chronic urological pain syndromes. The MAPP Study is now in its second phase and researchers hope to utilize gathered data on patient experiences with IC to identify different phenotypes of the disease. Phenotype information will ultimately allow physicians to prescribe treatments with more specificity. Research on chronic pain that is significant to the community is also supported by the National Institute of Neurological Disorders and Stroke (NINDS) as well as the National Center for Complementary and Alternative Medicine (NCCAM). Additionally, the NIH investigator-initiated research portfolio continues to be an important mechanism for IC researchers to create new avenues for interdisciplinary research.

ICA also supports the National Center for Advancing Translational Sciences (NCATS), including the Cures Acceleration Network (CAN). Initiatives like CAN are critical to overhauling the translational research process and overcoming the research “valley of death” that currently plagues treatment development. In addition, drug repurposement and other efforts led by NCATS hold the potential to speed access to new treatment for patients. ICA encourages support for NCATS and the provision of adequate resources for the Center in fiscal year 2014.

IC PUBLIC AWARENESS AND EDUCATION

The CDC IC Education and Awareness Program is critical to improving public and provider awareness of this devastating disease, reducing the time to diagnosis for patients, and disseminating information on pain management and IC treatment options. The program ensures that the latest advancements in IC treatment are quickly communicated to patients and providers.

The IC program has utilized opportunities with charitable organizations to leverage funds and maximize public outreach. Such outreach includes public service announcements in major markets and the internet, as well as a billboard campaign along major highways across the country. The IC program has also made information on IC available to patients and the public though videos, booklets, publications, presentations, educational kits, websites, self-management tools, webinars, blogs, and social media communities such as Facebook, YouTube, and Twitter. For healthcare providers, this program has included the development of a continuing medical education module, targeted mailings, and exhibits at national medical conferences.

The CDC IC Education and Awareness Program also provides patient support that empowers patients to self-advocate for their care. Many physicians are hesitant to treat IC patients because of the time it takes to treat the condition and the lack of answers available. Further, IC patients may try numerous potential therapies, including alternative and complementary medicine, before finding an approach that works for them. For this reason, it is especially critical for the IC program to provide patients with information about what they can do to manage this painful condition and lead a normal life.