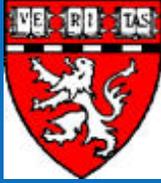


Genetic Study of IC/PBS/CPPS Newsletter

May 2010

Issue 3



Special Points of Interest:

- Meet Dr. Stuart Bauer
- Visit our Website!!
- Call/E-mail us about what you want in the next issue

IC/PBS/CPPS Family Enrollment Ongoing...

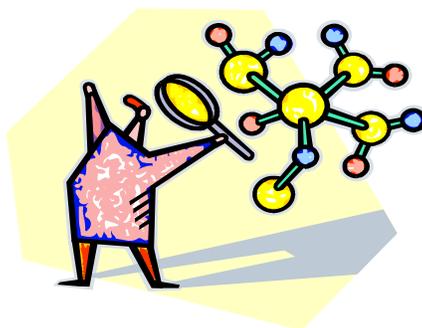
Interstitial Cystitis/Painful Bladder Syndrome/Chronic Pelvic Pain Syndrome (IC/PBS/CPPS) is a debilitating syndrome characterized by chronic pelvic pain, urinary frequency, and urinary urgency. To date, the cause of IC/PBS/CPPS remains unknown, but our study here at Children's Hospital Boston is working to discover an underlying genetic cause of this condition.

Many genetic diseases and syndromes are seen to "run" in families. They can be passed down through generations, just like the blue eyes from a grandfather or the red curly hair from a great-grandmother. To study the genetics of a disease or syndrome it is important to collect families with the diagnosis of IC/PBS/CPPS. We need both family members with the diagnosis IC/PBS/CPPS and family members

WITHOUT IC/PBS/CPPS symptoms in order for our study to be successful. To date, we have **enrolled 100 families** from the United States and Canada. Our goal is to enroll 500 families. Please help us to reach our goal by spreading the word and talking to your family members and your urologist. We welcome participants of all ages and genders to the study—men, women, girls, and boys.

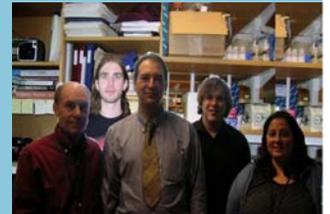
To enroll in our study or just get more information contact our study coordinator, Elicia Estrella, via phone at (617) 919-4552 or via e-mail.

We can do it with your help!



Meet the Team

From left front:
Louis Kunkel,
Steven Boyden,
Jordan Dimitrakov,
Sean Salinger,
Elicia Estrella



What is a Co-Morbidity?

Do you have bladder symptoms of IC/PBS/CPPS that occur alongside other secondary conditions? These secondary conditions are called "co-morbidities." Having two or more co-morbidities along with your urinary symptoms could be a diagnosis of IC/PBS/CPPS as well. Co-morbidities commonly seen with IC/PBS/CPPS include fibromyalgia, endometriosis, migraine and vulvodynia. We are interested in studying individuals and families with any or all of these disorders. The co-morbidities can be seen in individuals with IC/PBS/CPPS or their family members. If this sounds like you or your family Give Us A Call!

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We have moved to a new building...
Center for Life Sciences (CLS), 15th floor, Room 1531

Check us out on line! www.chb-genomics click on Interstitial Cystitis

Children & IC/PBS/CPPS



Dr. Stuart Bauer,
Dept. of Urology
Children's Hospital, Boston

Currently, most urologist use the the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) defined criteria to diagnose IC/PBS/CPPS. This criteria states patients must be at least 18 years old. This criteria was initially designed to help researchers design clinical trials to avoid the difficulty of obtaining informed consent of minors. Recent studies suggest by adhering to these criteria, the diagnosis of IC/PBS/CPPS is missed in over 60% of patients. Additionally, at least 25% of adults diagnosed with IC/PBS/CPPS

report having urinary tract problems in childhood, well before age 18.

Our study is interested in understanding and defining IC/PBS/CPPS in children. We are collaborating with Dr. Stuart Bauer, pediatric urologist at Children's Hospital Boston. Dr. Bauer cares for most of the IC/PBS/CPPS suspected children seen at Children's Hospital Boston. Dr. Bauer has a longstanding interest in bladder function in children and has referred many families to our research. With his help, we hope to better define IC/PBS/CPPS in the pediatric population. This may help us understand disease progression, promote earlier diagnosis, and improve treatment effectiveness.