



P.U.R.E. H.O.P.E.
Pelvic & Urological Resources & Education
Helping Others with Pelvic-Pain Everywhere

www.pure-hope.org

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2009 Pelvic Health Patient Education Day Summary
Houston, Texas

P.U.R.E. H.O.P.E. held its fourth annual conference on Saturday, January 24, 2009 in Houston, Texas. The conference had originally been scheduled for September 13, 2008, but Hurricane Ike forced a postponement. The conference was a full-day event attended by over 80 participants, which included not only patients, but also their spouses, family members, and friends. As those with pelvic health problems know all too well, a strong support network of doctors, family, and friends is essential in helping patients deal with the physical and emotional aspects of their conditions. Therefore, the P.U.R.E. H.O.P.E. representatives at the conference were very happy to see that so many patients were accompanied by family and friends.

P.U.R.E. H.O.P.E. (hereafter "PURE HOPE") is an acronym for "Pelvic & Urological Resources & Education – Helping Others with Pelvic Pain Everywhere." PURE HOPE was formerly known as the ICU of Texas, where ICU stood for "Interstitial Cystitis United." The name of the organization was changed because the organization itself has changed in so many ways during the past several years. The new name – PURE HOPE – is intended to reflect some of those changes. First, the organization has expanded its focus from being a predominantly IC education and support group to the much broader focus of pelvic health in general, as well as conditions – such as fibromyalgia – that appear may be related to chronic pelvic health problems. Second, the organization is growing geographically beyond just the Houston and Southeast Texas area, and is fast becoming a national organization serving patients throughout the United States, and even in a number of foreign countries. These changes were evident during the 2009 PURE HOPE conference. The expanded focus to cover not only IC, but other pelvic health issues and related conditions, was clearly demonstrated by the slate of speakers (discussed in more detail below) who addressed topics ranging from vulva-vaginal disorders to irritable bowel syndrome. The expanded geographic reach of the organization was demonstrated by the notable number of attendees who travelled from as far away as Indiana and Florida to join us.

This year there was a very special event on the day preceding the conference. On Friday, January 23, 2009, between 4:00 p.m. and 6:00 p.m., the "Meet the Doctors" reception was held at the Holiday Inn where the conference was to be held the following day. All five of the conference speakers (see below) attended the "Meet the Doctors" event, along with a number of representatives from both the PURE HOPE Board of Directors and the PURE HOPE Medical Advisory Board. Everyone who had registered to attend the conference was invited to the "Meet the Doctors" reception. This event provided the patients, family and friends that attended an opportunity to meet with the speakers in an informal setting and to talk with them "one on one." The reception was well attended, and received very favorable marks on the conference evaluation forms that were completed by attendees. Many thanks to Alaven, LLC for sponsoring the "Meet the Doctors" event.

The conference kicked off bright and early on Saturday morning. Cindy Sinclair, President of PURE HOPE, moderated the conference and introduced the speakers. There were five speakers at this year's conference, two in the morning and three after lunch. At the end of the morning and afternoon presentations, there was a Q&A session. Attendees were invited to write out any questions they might have for Cindy or the speakers on index cards, which were collected and then distributed to the appropriate speaker to respond.



- ✓ The first speaker was Theoharis Theoharides, M.D., Ph.D. Dr. Theoharides is a Professor of Pharmacology at Tufts University School of Medicine in Boston, and has also been very involved for many years in IC research. Dr. Theoharides's topic was **"Bladder Mastocytosis & Beyond."** Dr. Theoharides and his colleagues have focused very closely on the existence of mast cells (inflammatory cells) in IC bladders. They have used electro microscopy to see things that cannot be seen with normal pathology. Based on Dr. Theoharides's research, a product has been developed that is designed to treat the inflammation in the bladder. This product, which is produced by Alaven LLC, is called CystoProtek. Dr. Theoharides discussed the "ingredients" of CystoProtek, and explained why many patients obtain symptomatic relief from using CystoProtek. For more information regarding Dr. Theoharides and his mast cell research, visit www.mastcellmaster.com.
- ✓ The second speaker was Peter M. Lotze, M.D. Dr. Lotze is affiliated with the Obstetrics & Gynecology Associates, PA, in Houston, and is also an Assistant Professor at Baylor College of Medicine. Dr. Lotze's topic was **"An Overview of Managing Interstitial Cystitis & Associated Conditions."** Dr. Lotze focused on the basics of IC, including diagnosis and the critical importance of having a patient's full history. Dr. Lotze also emphasized that it is often key for a treatment plan to include more than one therapy, and he reviewed various treatment options that are currently available. From a patient's perspective, one of Dr. Lotze's slides hit the nail on the head. The slide stated that "No Man Is An Island," and emphasized how important it is for patients to have a broad support network consisting not

only of medical doctors to treat their physical problems, but also doctors or other professionals to assist with the psychological and emotional trauma caused by the physical problems, as well as family, friends, and support groups like PURE HOPE.

- ✓ Following the lunch break, the third speaker was Sandra Hurtado, M.D. Dr. Hurtado is also affiliated with the Obstetrics & Gynecology Associates, PA, in Houston, and she has a special expertise in vulvo-vaginal disorders. Dr. Hurtado's topic was "***Vulvar Pain: Focus on Vestibulodynia.***" Dr. Hurtado reviewed the different types of vulvo-vaginal disorders that have been identified, including an explanation of the variety of medical terms used to describe these disorders. She also reviewed the most commonly reported symptoms, as well as possible treatment options, associated with each type of vulvo-vaginal disorder. Dr. Hurtado indicated that vulvo-vaginal disorders are more prevalent than previously thought and that, although doctors still have much to learn in this area, much effort is being put forth to match theories of causation with effective treatments.
- ✓ The fourth speaker was Dr. Christopher Smith, M.D. Dr. Smith is an Associate Professor of Urology at Baylor College of Medicine, and is also a practicing physician. Dr. Smith's topic was "***Interstim and Botox: Merging Therapies to Treat Refractory Cases of Painful Bladder Symptoms & Chronic Pelvic Pain Conditions.***" Dr. Smith elaborated on these two specific treatment options for OAB (Overactive Bladder) and IC (Interstitial Cystitis), which often co-exist in patients. Dr. Smith is well-known nationally for his use of these two therapies in connection with "difficult-to-treat" cases of IC and related conditions. Interstim is an implant that relies on sacral nerve stimulation to address the nerve component of urinary control and pelvic pain symptoms. Interstim therapy can often be effective in patients who have failed more conventional therapy. Botox is short for botulinum toxin and – yes – it is the same botox that is used by dermatologists and cosmeticians to reduce wrinkles. The current therapy is to inject botox into the bladder or into the pelvic floor to control symptoms caused by OAB, IC, or pelvic floor dysfunction ("PFD"). Patients who obtain relief from Botox injections often continue to have relief for as long as 5 or 6 months, at which time the procedure can be repeated.
- ✓ The fifth and final speaker was Michael Pezzone, M.D. Dr. Pezzone is an Associate Professor of Medicine and Pharmacology at the University of Pittsburgh. Dr. Pezzone's topic was "***Irritable Bowel Syndrome & Overlapping Chronic Pelvic Pain Disorders.***" Although Dr. Pezzone focused during his presentation on the symptoms and treatment options relating to irritable bowel syndrome, he emphasized that IBS patients also often suffer from other chronic pelvic pain conditions. In fact, the overlap of these conditions can go beyond the pelvis and become systemic, as in the case of conditions like fibromyalgia. The prominence of the overlap between IBS and these related conditions was evident by the large number of questions posed by the audience that were addressed to Dr. Pezzone.

The conference started at 8:00 a.m. and lasted until 4:30 p.m. It was a very long day, but also hopefully a very informative and productive day for all who attended. All five of the speakers are well-known in their practice areas, and shared a wealth of knowledge and experience during the course of their presentations. As all of us know, chronic pelvic health conditions can be very difficult to diagnose and treat, and we are so grateful to have dedicated researchers and doctors such as our five speakers, as well as all the members of the PURE HOPE Medical Advisory Board, on our side and by our sides, working together with us to find effective treatments.

There are many "thank you's" in order for those who contributed to making the 2009 PURE HOPE conference a great success. First, we want to thank all the attendees. We hope you learned a lot, met some new friends, and plan to attend next year's conference. Second, we want to thank the speakers who worked hard to develop presentations to impart as much helpful information as possible, and to respond to all the questions presented during the Q&A sessions. Third, we want to thank all of the sponsors that provided financial support so that the conference could take place. These include Alaven, LLC; Ortho McNeil Women's Health & Urology; EMPI Recovery Sciences; Medtronic Interstim Therapy; and Desert Harvest (who also provided the delicious breakfast). These five sponsors also had vendor booths set up during the conference to consult with attendees (and hand out little "goodies"). A number of other vendors also maintained booths throughout the

conference, including: Uroplasty, Inc.; Houston Colorectal Associates; and Fred Emmite, Nutritional Consultant / Pharmacist. Fourth, we want to thank the members of the PURE HOPE Board of Directors and Medical Advisory Board that took time out of their busy schedules to attend the conference. Finally, a big round of applause goes to Cindy Sinclair, President of PURE HOPE, and to Tina Dodd, Vice President of PURE HOPE, whose continuing hard work and dedication in connection not only with the conference, but also with all PURE HOPE activities, is truly a blessing.

Since the conference was held in January 2009, the PURE HOPE Board of Directors and the Medical Advisory Board are already discussing plans for the 2010 conference. More information will follow on next year's conference in upcoming newsletters. If you have any suggestions or ideas for the conference, please don't hesitate to send them to csinclair@pure-hope.org. Likewise, if you have any questions regarding PURE HOPE or want to talk with someone about your pelvic health problems email csinclair@pure-hope.org or visit our website at www.pure-hope.org.