International Consultation on Interstitial Cystitis in Japan
23-25 March 2007, Kyoto Japan

Following the success of the 1st ICICJ in 2003, the Japanese urologists once again organized a symposium and international consultation on interstitial cystitis in Kyoto this year.

While the Japanese urologists were able to enjoy the latest insights on diagnosis and treatment from international invited speakers, time was also reserved for international discussions on the hot topic of nomenclature (what name do we call it?) and definitions, leading to often heated discussions. Not surprisingly, no agreements were reached. A possible definition was put forwarded that is already being hotly disputed.

IPBF Board Member, Dr Nagendra Mishra from India, was invited to Kyoto to speak on the Indian situation. Dr Mishra has written about his own experience of this Kyoto meeting for our website.

ICICJ – Kyoto Japan

by Nagendra Mishra MD

ICICJ was held in Kyoto, Japan from 23 to 25 March 2007. One of the aims of this meeting was to reach consensus about the name, definition, diagnostic investigations and treatment algorithm. It was a very successful conference insofar as there was a great deal of discussion, but the consensus and the final draft of the name, definition and treatment algorithm has not been framed. The investigation protocol discussed is same as ESSIC (European Society for the Study of IC?PBS) with few changes, but it is not clear which test is optional and which test is a must.

As far as the name is concerned, it was felt that the name interstitial cystitis should be retained. It was also felt that there is a need to change the name as it leads to lot of research in the wrong direction all over the world. At the Kyoto meeting, it was the American ICA patient organization and ICA Germany who did not want any change in the name. As a representative of IPBF, I also spoke to retain the name interstitial cystitis. The consensus was that the name interstitial cystitis will definitely remain as a part of the new nomenclature. Another important point discussed was that the name painful bladder syndrome is also good, whereas the IASP taxonomy task force prefers bladder pain syndrome. We will have to wait until the summary statement from the meeting is published for more details. The Japanese group of urologists
was in favour of a new umbrella term: hypersensitive bladder syndrome (HBS) as presented by Professor Yukio Homma.

The definition will probably be a hybrid of the ESSIC and AMERICAN definitions taking a few words from both. I myself argued for removal of the word bladder as bladder pain restricts the definition, whereas pelvic pain seems to me to be a better terminology. Pelvic pain of bladder origin is again difficult to define and will not include scrotal, perineal, urethral, and anal pain. It was agreed by all that urgency is an important aspect of interstitial cystitis and should therefore be included in the definition. The term persistent urge was not acceptable to all. There is every chance that the term confusable disease will be retained despite American resistance.

Symptoms and history taking were discussed in detail. I myself pointed out that it should not be forgotten that IC patients may present with other symptoms such as slow stream, dribbling, a desire to pass urine immediately after micturition, a feeling of incomplete evacuation and anal discomfort. The consensus was that the ESSIC model can be followed with a few changes. The potassium test was removed from the list and it was emphasised that urodyamics and biopsy are optional investigations. There was lot of apprehension about taking three deep biopsies and their usefulness. The ESSIC method of sub-classifying the patients was appreciated by all.

Professor Philip Hanno gave an excellent presentation on treatment. He pointed out that cyclosporine is emerging as one of the very promising drugs.

Dr. Lee Nyberg caused quite a stir in his speech when he declared that NIDDK/NIH is now changing gear. He said that although we have been able to increase awareness about the disease all over the world among doctors, patient support groups and patients, we have really not achieved anything with regard to treating the disease. There is a need to change gear and the NIDDK will hold a meeting in the autumn of 2007 to re-define the research definition. They plan to make the research definition less “bladder-centric” and make it more patient-centric and more holistic, focusing on IC as a systemic disease, with manifestations in the bladder, but also with other manifestations too and will involve doctors from other disciplines as well. There will also be involvement of international doctors with an interest in the disease.

The presentation that made the greatest impression on me personally was that of Dr Naoki Yoshimura who spoke on basic research. He made this difficult subject so easy and understandable that the audience was spellbound for the 45 minutes he spoke. He gave a vivid description of the research work which included work carried out by their own group. It is my firm belief that his group working at Pittsburgh has contributed a great deal to basic IC research and his concept of neurogenic inflammation, C-fibre sensitization and organ cross-talk convinced all the delegates present there.

Around 100 delegates attended the meeting, largely from Japan. One third of the delegates were from drug companies. There were two patient organization represented, 2 representatives from the NIDDK/NIH, and 24 international speakers including 11 from Korea and Taiwan. All the speakers gave excellent presentations. All aspects of IC were discussed.

The social evenings after the meeting were also well attended with Japanese hospitality at its best. The scientific programme was a tight schedule and left all of us very tired since the international delegates were also struggling with jetlag. Professor Tomohiro Ueda, Professor
Philip Hanno, Professor Jorgen Nordling and Dr Vicki Ratner deserve a lot of applause for the success of the meeting. Professor Ueda promised to hold an ICICJ meeting every 4 years. Delegates to the ICICJ meeting had the unexpected ‘bonus’ of an earthquake laid on! However, the question & answer session continued unabated, regardless of the fact that the building was shaking around the delegates!