

INTERNATIONAL CONSULTATION ON INTERSTITIAL CYSTITIS, JAPAN

28-30 March 2003, Kyoto

First step taken towards redefining IC

The International Consultation on Interstitial Cystitis Japan (ICICJ), held in Kyoto from 28-30 March 2003, was the culmination of many months of intensive work by Dr Tomohiro Ueda and the ICICJ Organizing Committee. 25 international specialists and 26 Japanese urologists gathered in Kyoto for intensive brainstorming on diagnostic criteria for IC. Although the war in Iraq threatened to disrupt the entire meeting, it nevertheless went ahead with only five American participants unable to attend, including moderator Dr Susan Keay who was replaced at the last minute by Dr Philip Hanno. Participants in the workshops included urologists, (uro)gynaecologists, an internist-pharmacologist and an internist-immunologist from 16 different countries from all 5 continents. Truly international in scope. Observers included representatives from a number of pharmaceutical companies.

This unique meeting formed the first important step in a multi-stage international approach aimed at redefining IC and drawing up new evidence-based criteria for the diagnosis of this condition.

Step 2 in this process is discussion and dissemination of the preliminary results that emerged from the Kyoto meeting through publications, presentations at meetings, discussions at society congresses such as the AUA, ICS, EAU, BAUS, IUGA, followed by refinement and further discussion at the NIDDK/ICA IC scientific symposium in October 2003 on "Research Insights into Interstitial Cystitis" in Washington DC.

Step 3 will take the form of a Consensus Conference to make final changes and formally adopt new criteria. It should be emphasized that this will not happen overnight and is likely to be a process of at least two years.

Discussions in Kyoto throughout the day on 29th March and the morning of 30th March centred round the following nine interactive workshops:

Workshop 1

IC, gynaecologic pelvic pain, prostatitis and their epidemiology
moderator: Ananias Diokno MD
co-moderators: Yukio Homma MD, Yasuyuki Suzuki MD, Yuki Sekiguchi MD

Workshop 2

Research criteria versus clinical criteria for IC: what is the value of each?
moderator: Christopher Payne MD
co-moderators: Akito Terai MD, Kazuto Komatsu MD

Workshop 3

Pathology of IC
moderator: Anna Rosamilia MD
co-moderators: Yasuhiko Igawa MD, Shin Higashi MD

Workshop 4

Cystoscopy, hydrodistention: what is their place to be in the diagnosis of IC?
moderator: Hans Rabe MD
co-moderators: Momokazu Gotoh MD, Hitoshi Momose MD

Workshop 5

Urodynamics and IC
moderator: Paul Irwin MD
co-moderators: Mineo Takei MD, Yoshio Sugino MD

Workshop 6

Clinical symptoms scale for IC:
- for diagnosis
- for following the course of the disease
moderator: Lowell Parsons MD
co-moderators: Takaaki Ito MD, Hikaru Tomoe MD

Workshop 7

Current and future directions in diagnostic markers in IC
moderator: Susan Keay MD (replaced by Philip Hanno MD)
co-moderators: Masayuki Takeda MD, Masahiro Tamaki MD

Workshop 8

Future research needs for the definition/diagnosis of IC
moderator: Jurjen Bade MD
co-moderators: Osamu Ishizuka MD, Masaki Yoshida MD

Workshop 9

Systemic aspects of IC, immunology, linkage with autoimmune disorders
moderator: Joop van de Merwe MD
co-moderators: Tetsuo Yamada MD, Yasuki Sakamoto MD

Each moderator opened the workshop by giving a short presentation on the current situation relating to his/her workshop, followed by lively, in-depth discussions. Simultaneous interpreting was provided throughout. These discussions continued informally in the evenings and during the wonderful social programme, with everyone giving their own opinions and theories on aspects of IC related to diagnostic criteria.

Summaries of each workshop were presented by the nine moderators during the plenary session on the afternoon of 30th March. The summary recommendations included areas of agreement, areas of disagreement, proposals for resolving differences, study proposals etc.

The proceedings and summaries will be published in the late summer in a special supplement to the International Journal of Urology.

All proceedings in Kyoto were recorded on video. The sale of the tapes to researchers, clinicians etc will be used to cover some of the expenses of organizing and running the ICICJ.

Patient representatives

The ICICJ meeting was also attended by patient representatives from a number of countries: Jane Meijlink (Netherlands), Anthony Walker (United Kingdom), Barbara and Juergen Hensen (Germany), Dot Milne (New Zealand) and Loredana Nasta (Italy) together with Masako Katsurada from Japan. Due to the war in Iraq, Dr Vicki Ratner and Ann Chesnut were unfortunately unable to attend. This meant that Dr Ratner's presentation on the work of the ICA in the first part of the plenary session on 30th March was given by Dr Robert Moldwin.

Presentations were also given by Jane Meijlink (IC and associated disorders), Barbara Hensen (IC and Diet), Anthony Walker (IC patient movement: from national to international) and Masako Katsurada on her experiences as an IC patient in Japan and the setting up of the Japanese patient association Tomonoki of which she is the very energetic and enthusiastic chairman. The audience of 130 people in the plenary session included 40 Japanese patients in addition to doctors and researchers.

Global patient meeting

On 29th March, a wonderful international patient meeting was organized at the Century Hotel in Kyoto, sponsored by Tomonoki, the Japanese patient support group. This was an amazing experience. A room, beautifully decorated with traditional Japanese handwork, was filled to the brim with Japanese IC patients. Ninety people attended including patients, their relatives and organizers. Each table of Japanese patients was joined by a patient representative from abroad and a very essential interpreter. This led to a fascinating exchange of information and experiences (all via the interpreter) and the Japanese patients were eager to ask the international representatives many questions about IC. We in turn were very interested to hear the very positive experiences of Japanese patients with IPD, a new oral medication that has been the subject of trials in Japan by Taiho and that is to be further developed and distributed in the rest of the world by Yamanouchi that has signed a license agreement with Taiho.

The event in Kyoto was a tremendous boost to Tomonoki that will undoubtedly now go from strength to strength. A great deal of publicity was given to the ICICJ and the patient association, resulting in a large number of telephone calls from Japanese patients. The ICICJ meeting will have greatly increased awareness of IC among the medical profession in Japan and this will ultimately be of enormous benefit to patients.

JUA congress, 2-5 April 2003, Tokushima

Two days of sightseeing in Kyoto were followed by a journey by bus to Tokushima (with more wonderful sightseeing en route) for the annual congress of the Japanese Urological Association (JUA). Jane, Anthony, Barbara, Juergen and Masako participated in this event, together with Dr Hanno, Dr Sant, Dr Yoshimura and Dr Ueda.

An IC patient booth was organized for the very first time in Japan at the JUA congress, sponsored by the JUA. When we arrived on the first morning of the congress, the IC info table was standing all ready, including a TV running the video film

made of the patient meeting on 29th March in Kyoto. Although Masako Katsurada and helpers were running the info table for the very first time, they immediately got into the swing of things and presented many Japanese urologists with information on IC, including information on Dr Ueda's excellent book on IC in Japanese.

Satellite symposium

A satellite symposium on the State of the Art of Interstitial Cystitis was held at the JUA congress, sponsored by Taiho Pharmaceutical Co. Ltd, with presentations by Dr Sant on the pathophysiology of IC, Dr Hanno with a treatment update on IC, Dr Yoshimura on the pharmacology of IC and Dr Ueda rounded it off by presenting a summary of the highlights of the ICICJ.

IC World impulse

Following the Kyoto meeting, the world IC movement will never be the same. This unprecedented international brainstorming meeting has set an unstoppable process in motion. During their stay in Kyoto, IC doctors from around the world who had never met each other before became the greatest of friends and made plans that will form the basis of international cooperation and studies in the future.

And IC in Japan will never be the same either. It is to be hoped that the effects in Japan will ripple outwards to other countries in South-East Asia.

Much work ahead

Much work lies ahead of the international clinicians and researchers before ultimately reaching their target. But the first important step has now been taken and the clock can now never be turned back.

Thanks

Many thanks are due to Dr Ueda for taking this initiative, to the Organizing Committee for their hard work and to the JUA and SICJ in Japan for their sponsorship and support and to all the many other sponsors without whom it would not have been possible.

Special thanks to Ms Kiyomi Noguchi, Japanese congress secretary, and her helpers who looked after all participants fantastically well and helped to make their visit to Japan an unforgettable experience.