

Summary of the year 2003 for the ICA Germany

- ✓ Patients in Nuremberg, Teltow and Cologne celebrated the 10 year anniversary of the ICA Germany
- ✓ Specialized training for physicians in Cologne
- ✓ International cooperation
- ✓ Lecture at the European School of Urology (ESU)
- ✓ Lecture at the ICICJ in Japan – new cooperative efforts in IC research
- ✓ IC - State of the Art - the world's first IC reference book on CD-Rom
- ✓ New member newspaper and telephone consultation for patients
- ✓ Participation at the German Urological Society (DGU) Congress, the North German/Berlin Urological Congress, the Brandenburg Urological Congress, the North Rhine-Westphalia Urological Congress, the Berlin Self-Help Meeting, the Regional Working Group in Support of the Handicapped (LAGH) Self-Help Meeting and, through our partner organization ICA Austria, the Bavarian-Austrian Urological Congress.
- ✓ Participation in international congresses of the ICS, AUA, EAU, JUA and at the International Congress of Gynecology in Berlin
- ✓ Participation at the Society for Incontinence Help (GIH) Congress in Berlin
- ✓ Founding of the first multinational IC association MICA
- ✓ Visits to doctors, hospitals, pharmaceutical companies and representatives of the press
- ✓ Presentations by members of the Medical Advisory Council at a number of specialized training events
- ✓ Internet representation with more 9,000 call-ins: www.ica-ev.de
- ✓ Publications in various illustrated magazines and periodicals
- ✓ Publications in Urologische Nachrichten (Urological News)
- ✓ Answers to countless written requests for advice
- ✓ General assembly of the members - 2003
- ✓ Meeting and election of the Medical Advisory Council

General assembly of the members in Euskirchen

The general assembly of ICA members was held in Euskirchen. All issues concerning the association itself were also dealt with, as described in the invitation. The president Bärbel Mündner-Hensen and the treasurer Hildegard Kallabis were confirmed in their positions. The work of the management board is on an honorary basis and without payment.

Patients in Nuernberg, Teltow and Cologne celebrated the 10th anniversary of the ICA Germany

Meetings bringing patients together under the direction of the state coordinators Renate and Ernst Nuber in Nuremberg, Horst and Charlotte Krause in Teltow and Jürgen Hensen in Cologne were immensely successful. Intensive exchange of experience, workshop and balm for the soul will be permanent components of these meetings. In 2004 as well, we will organize three or four events over the entire country. The dates and places are not yet fixed. Suggestions for the areas Southwest Germany and Northeast Germany are still being gratefully accepted.

Specialized training for physicians

The members of Medical Advisory Council are actively engaged in specialized training for physicians and make use of every opportunity to convey information about IC. Together with Dr. Rudolf Stratmeyer of the "Left of the Rhine" interdisciplinary hospital in Cologne-Rodenkirchen, the ICA itself organized a special training session in Cologne for more than 60 persons. Speakers were Bärbel Mündner-Hensen, Dr. A. Wördehoff, non-tenured lecturer Dr. F. Oberpenning, Dr. R. Stratmeyer, Dr. A. van Ophoven, non-tenured lecturer Dr. W. Vahlensieck and Professor S. Störkel.



Visits to congresses

We always make use of opportunities to speak with representatives of pharmaceutical companies at several gynecological and urological congresses. At the same time, we provide information about IC, the work of the association, possibilities for sponsoring, maintaining contacts, etc., etc., etc.... We will continue to do this in the future. Our congress stand is regularly visited by physicians. For the first time, we were also present at the Society for Incontinence Help (GIH) Congress in Berlin. In this connection, we wish to especially thank Ms. Thiel of the GIH. In 2003, our congress stands were **occupied** for a total time of **38 days!**

International contacts

The ICA Germany enjoys an excellent reputation internationally. We maintain international contacts in the interest of being able to be directly involved in offering better diagnosis and therapy.

"American Queen of IC" made honorary member

20 years ago Dr. Vicki Ratner founded the Interstitial Cystitis Association in the USA and thus laid the foundation for modern research into the difficult clinical picture of IC. It is through her efforts alone that IC now occupies a firm place in medicine in the USA, is the subject of active research and receives continuous support. For these services, Dr. Vicki Ratner has been made an honorary member of the ICA Germany.



ICICJ meeting in Japan

At the invitation of our Japanese friends, an international IC Consensus Meeting was held in Kyoto, Japan for the purpose of clearly defining the dis-

ease. We came very close to reaching a clear definition. In Europe, this idea was taken up again at a meeting in Copenhagen. Our Medical Advisory Council member, non-tenured lecturer Dr. Oberpenning from Bonn, was instrumental in helping to formulate the European IC Guidelines.

Patient meeting in Japan and Japanese Urological Congress

In Japan we were warmly welcomed by Masako Katsurada, president of the Japanese patients' association TOMONOKI. We presented the ICA and our ICA patient study. This met with enormous interest. We had a joint congress stand at the JUA Congress. Our work together is outstanding.

Lecture at the European School of Urology (ESU)

For the first time, an IC seminar was offered at the German Urological Society (DGU) Congress in Hamburg. Professor Nordling (Copenhagen) presented the subject of IC. Bärbel Mündner-Hensen gave an impressive presentation of the clinical picture from the point of view of the patient and also published the ICA patient study What Helps – What Harms?

International congresses and fairs

Together with our MICA partners and our closely allied organizations TOMONOKI in Japan, ABATYCI in Spain, and BPSA in England, our IC organization is very well represented internationally. Thus, MICA was assigned the stands at international congresses and demonstrated our common goals: improving diagnosis and therapeutic capability, providing information, supporting research, and cooperation. At the American Urological Association (AUA) Congress in Chicago, the most important urological congress in the world, we had a stand together with the ICA-USA and AICI of Italy. We also shared the ICS congress stand with our Italian friends, as well as the stand at the EAU Congress with our Spanish friends. At the Japanese congress, the ICA was present together with TOMONOKI and the AICI.

Internet: www.ica-ev.de and multinationalica.org

With the help of computer specialists we have now made further advances with Internet representation. We will persist in further improving our representation in this area. The communication and presentation area is a very important area for our future work and will continue to gain in importance. Our website was visited more than 9,000 times. The design, under the responsibility of our friend Dieter Kabatnik is becoming increasingly more professional.

Founding of the multinational IC association MICA

The ICA Germany is a cofounder of the first international charity organization for the clinical picture

of interstitial cystitis. The new group has the name "Multinational Interstitial Cystitis Association", abbreviated **MICA**. The founding members of this dynamic new organization are the representatives of the patient associations of the ICA Austria., ICA Germany, AICI (Associazione Italiana Cistite Interstiziale) and the ICA-USA (The Interstitial Cystitis Association). IC charity organizations around the world are cordially invited to become members of the multinational IC organization. This of course also applies to physicians and scientists of all disciplines, as well as corporations and institutions concerned with interstitial cystitis. The founders of the MICA Medical Advisory Council are: Professor Mauro Cervigni, Italy; Professor Roberto Carone, Italy; non-tenured lecturer Dr. Frank Oberpenning, Germany; Dr. Arndt van Ophoven, Germany; Professor Helmut Madersbacher, Austria, Professor Claus Riedl, Austria; Professor Alan Wein, USA, Professor Philip Hanno, USA, Professor Robert R. Moldwin, USA, Professor Christopher Payne, USA, and Professor Tomohiro Ueda, Japan. Special Consultant is Professor Monica Liebert, Director of Research of the American Urological Association. Senior Consultants from Germany are already Professor Lothar Hertle (Münster), Professor Dieter Jocham (Lübeck), non-tenured lecturer Dr. Winfried Vahlensieck (Bad Wildungen), Dr. Alois Wördehoff (Euskirchen), and Dr. Rudolf Stratmeyer (Cologne); additional members and consultants will be added later.

We have accepted a challenge and established the foundation for proper international cooperation with **MICA**.

New: senior ICA consultants

It has been and is still the goal of the ICA to build up a network of interested and committed physicians in Germany as contact persons for patients seeking help and advice. Committed practicing physicians play a particularly important role in this development. Members from the beginning are: Dr. Evecek (Mönchengladbach), Dr. Wu (Euskirchen) and Dr. Loch (Homburg/Saar).

Publications

A new newspaper for members and large number of publications in magazines and newspapers stirred considerable interest. We did not count the addresses and telephone calls, especially in view of the reports in well known daily newspapers in the Berlin and Cologne areas, customer publications in pharmacies, the newspaper published for members of the Barmer substitute health insurance scheme and various "women's newspapers".

Patient telephone

Persons seeking advice in connection with IC call us every day:

The new ICA telephone number is:

0049-2697-906306

IC state of the art – the first IC reference book in Europe

The ICA Meeting and the 6th International IC Symposium in Hamburg in 2001 provided the basis for the book about IC, published in a two-language edition at the end of August, 2002. The book has found wide use, with the result that the book is no longer available. Much less expensive is the **IC-State of the Art** CD-ROM, available from the ICA.

We are grateful to all those who have supported the ICA Germany within their means with large and small contributions.

We wish to thank non-tenured lecturer **Dr. Winfried Vahlensieck**, head of the Medical Advisory Council, and all active **members of the Medical Advisory Council** for their cooperation with us.

We are also grateful to the **state coordinators Charlotte and Horst Krause** (Teltow), **Irmgard and Wolfgang Leser** (Jesteburg), and **Renate and Ernst Nuber** (Nuremberg) for their untiring and friendly efforts.

Thanks are due for the special support of **Wolfgang and Irmgard Leser** (Jesteburg) with their "Art for the Benefit of the ICA" campaign.

We also extend our sincere gratitude for their special support in 2003 to:

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★ **Medical-Service**, Bad Liebenzell
★ **Cytochemia AG**

- **BARMER Ersatzkasse (Barmer substitute health insurance scheme)**, Wuppertal
- **AOK-Bundesverband (regional public statutory health insurance confederation)**, Bonn
- **DAK Deutsche Angestellten Krankenkasse** (health insurance company for private-sector employees in Germany)
- **Sponsor pool** "partners for self-help" of the confederation of company health insurance plans (BKK), the confederation of guild member health

insurance plans (IKK), the confederation of agricultural health insurance plans, the federal miners' health insurance plan, and the seamen's statutory health insurance plan.

- **Joint self-help sponsorship of the substitute health insurance schemes**
of the Techniker Krankenkasse (Technical Health Insurance Scheme), KKH Kaufmännische Krankenkasse (Commercial Health Insurance Scheme), the Hamburg Münchener Krankenkasse (Hamburg Munich Health Insurance Scheme), the HEK-Hanseatische Krankenkasse (Hanseatic

Health Insurance Scheme), the HZK-Krankenkasse für Bau- und Holzberufe (Health Insurance Scheme for the Building and Woodworking Professions), BRÜHLER-Die Krankenkasse (The Health Insurance Scheme), Buchdrucker-Krankenkassen Hannover (The Printers' Health Insurance Scheme Hanover), and the KEH Ersatzkasse (KEH Substitute Health Insurance Scheme).

- Gmünd Substitute Health Insurance Scheme (**GEK**)

References to the literature:

- „**Interstitielle Cystitis-2000**“ ("**Interstitial Cystitis-2000**"), special paper from the ICA Germany easily understandable general description of IC, 10 Euro fee to cover cost of printing
- „**IC-State of the Art**“ als **CD-Rom** ("IC-State of the Art" as CD-Rom (pdf file)
available from the ICA Germany, Untere Burg 21, 53881 Euskirchen
10 Euro for members, 20 Euro for non-members, plus shipping costs
- „**Endlich Schluss mit Blasenentzündungen**“ ("At Last No More Inflammations of the Bladder")
by Silvia Knöpfel - with a large section devoted to IC,
Trias Verlag, Stuttgart, ISBN 3-8304-3081-7, 12.95 Euro
With a foreword by the ICA Germany
- „**Blasenentzündungen, Blasenschmerzen ...damit müssen Sie nicht leben!**“
("Inflammation of the Bladder, Bladder Pain ... You Don't Have to Live with This any Longer!")
by Dr. Ines Ehmer, DOC-Durchblick Verlagsgesellschaft, Dachau 2003, ISBN 3-9808824-0-3

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