

9th IOF World Wide Conference of Osteoporosis Patient Societies

Istanbul, Turkey, September 4-7, 2003

"We hope the conference will be stimulating for you, helping to cement ideas and friendships and encouraging you to create new programs or enhance existing ones when you return home."

IOF CEO Daniel Navid
addressing the conference delegates



IOF CEO Dan Navid thanks Gulseren Akyuz of the Osteoporosis Patient Society of Turkey for her society's warm hospitality and excellent organization

Most of the almost 150 delegates from 45 countries who attended the recent IOF World Wide Conference of Osteoporosis Patient Societies (IOF-WWC) in Istanbul would agree that the conference was an unparalleled success. There was a tangible feeling of common purpose and friendship among the delegates that can in no small part be attributed to the warm hospitality and excellent on-site organization of the host society, the Osteoporosis Patient Society of Turkey. An excellent program, challenging workshops and memorable evenings held in historic surroundings all served to make the conference a unique experience.

Below is a brief outline of the conference program and related activities:



Media Training

Layla Audi of the Jordanian Osteoporosis Prevention Society (left) and Irit Inbar of the Israeli Foundation for Osteoporosis and Bone Diseases were two of the 16 delegates who attended the media training.

On September 4th, two training sessions given by professional media experts were held for a small group of participants. As patient society representatives are often required to speak to journalists, the training sessions were intended to help participants develop a clear and effective technique in dealing with the media. The trainers provided one-on-one analysis and valuable feedback to show participants how they could improve their communication style when speaking in front of a camera. IOF thanks Roche and GSK who kindly sponsored and helped with the logistics of the training sessions.

Press Conference

Close to 20 journalists from local and national TV and newspapers attended the late afternoon press conference organized on September 4th by Dr. Gulseren Akyuz of the Osteoporosis Patient Society of Turkey. The conference was held to present the first data showing Turkish fracture rates based on a large sample (8,000 people) and to raise awareness of the disease which remains largely neglected perception is that osteoporosis is merely a symptom of menopause.. Camera lights flashed with the arrival of the society's patron, the famous actress Filiz Akin. Ms. Akin supports the cause of osteoporosis in her role as the society's patron and has done much to raise the profile of the disease in Turkey. With her elderly mother in mind, Ms. Akin commented, "I don't want people to suffer if osteoporosis can be prevented". In addition to Filiz Akin and Gulseren Akyuz, speakers at the press conference included Dr. Ahmet Zeki Segnil (Head of the Health Department of Istanbul Municipality), IOF CEO Daniel Navid and Paul Sochazcewski, IOF head of communications.



From left: Dr. Gulseren Akyuz, Filiz Akin and Dr. Ahmet Zeki Segnil

Opening session



Dr. Rustem Zeydan, Undersecretary of State

The conference was launched with a **welcome address** from IOF's CEO Daniel Navid and the Turkish hosts – Gulseren Akyuz, Filiz Akin, and special honored guest Dr. Rustem Zeydan, Undersecretary of the Ministry of Health of Turkey. Stating that "Collaboration is a must in the struggle against osteoporosis," Dr. Zeydem congratulated participants for the important role they are playing in increasing osteoporosis awareness.

Dr. Helmut Minne, Vice Chairman of IOF's Committee of National Societies, paid **homage to the late Linda Edwards**, who, as Chair of the National Osteoporosis Society of the UK, had established the first World Wide Conference of Osteoporosis Patient Societies in 1995. Dr. Minne announced that, as a tribute to Linda's pioneering work, IOF would offer a grant of SFr. 20,000. to one deserving IOF member society at each IOF WWC meeting, beginning in Istanbul. Paul Sochazcewski, IOF's head of communication, followed up on this good news with a presentation showing the broad range of projects carried out by IOF in the past year and planned for the coming World Osteoporosis Day.



A memorable **keynote address**, "How international NGO's change the world", was given by Anthony Phelps, McCann Erickson Healthcare regional director and creator of "Finding the Magic and Self Mastery Seminar Series". Utilizing an ancient Indian story as an allegory, Mr. Phelps' talk centered on the power of each individual to achieve change by maintaining an unwavering focus on his/her goals and remaining true to him or herself.

Open mike presentations by IOF member societies show how the osteoporosis movement works across a broad cultural and geographic range. Most importantly, the open mikes are a source of inspiration for the attendees who have the opportunity to view the projects and successes of other societies. In Istanbul, open mike presentations were given by delegates from Iran, Panama, Romania and Singapore.

- **Dr. Bagher Larijani**, Iran introduced the ambitious work of the Endocrinology & Metabolism Research Centre of Tehran University which is carrying out, among other projects, a national plan for osteoporosis and designing a vitamin D fortification program.
- **Dr. Joan Levin** of the Fundacion de Osteoporosis y Enfermedades Metabolicas Oseas of Panama described her creative approach to getting high-profile celebrity patronage and government support for an osteoporosis risk test distribution and survey.
- **Dr. Andrea Gasparik Ildiko** of the Association for the Prevention of Osteoporosis in Romania discussed her society's projects including the successful TV ad campaign which helped drive the society website to the top in the country's rankings.
- Finally, **Louisa Zhang** of the Osteoporosis Society of Singapore outlined her society's many and varied activities, stressing how helpful it is to have a supportive and prominent patron. Louisa not only shared her recipe for success – she also treated delegates to a recipe for nutritious spring rolls!



Open mike speaker Dr. Bagher Larijani, Iran



Dr. Joan Levin, Panama

Workshops

Skill-building workshops are an integral part of the IOF-WWC. Attendees were asked to attend two of the five different workshops which were held on each day of the conference.

- The workshop on policy and lobbying, led by Judy Stenmark (Osteoporosis Australia), focused on strategies to help move government and health care authorities towards positive policy change in relation to the diagnosis and treatment of osteoporosis.
- "Getting Press and TV coverage", led by IOF's Paul Sochazcewski, helped participants learn how to attract the interest of journalists, hold effective press conferences and write gripping press releases.
- Joyce Gordon and Sue Berlove of the Osteoporosis Society of Canada held a workshop on effective management structure, an important element in establishing and maintaining a well-run patient society.
- Claire Hammond, education advisor of the National Osteoporosis Society UK led the workshop entitled "Creating effective education programs". This was focused on strategies to use in order to develop a bone health teaching program and have it successfully integrated into the school curriculum.
- The workshop "Non-pharmaceutical support to people with osteoporosis" was led by Dr. Maria Luisa Bianchi (Lega Italiana Osteoporosi). Participants discussed the importance of psychological support, nutrition, exercise and non-drug pain relief for patients, and how to integrate this into societies' programs.

The IOF-Linda Edwards Memorial Award

Given to a deserving IOF member society whose work exemplifies Linda's spirit – "thinking big", practical and effective projects, devoted staff, imagination, scientific credibility -the memorial award, valued at 20,000 Swiss francs, was presented for the first time in Istanbul. The winner was a young and active patient society from Romania – the Association for the Prevention of Osteoporosis in Romania (ASPOR).



Andrea Gasparik Ildilko and Gaby Dragoi received the IOF-Linda Edwards Memorial Award

The IOF-Lilly Policy Initiative Grants



Leonor De Villafranca, representing COMOP, was just one of the many happy winners of IOF-Lilly grants

Delegates from Bulgaria, Chile, Lebanon, Mexico, and Poland were thrilled when their society's names were called to receive valuable grants of 10,000 USD. The IOF-Lilly Policy Initiative Grants, awarded to five societies every two years beginning in 2003, honor societies for their innovative projects in osteoporosis advocacy. Lilly representative Sondra McQueary and IOF CEO Daniel Navid personally congratulated and gave certificates to the winners: Women without Osteoporosis (Bulgaria); the Fundacion Chilena de Osteoporosis; the Lebanese Osteoporosis Prevention Society; the Healthy Bone Enthusiasts Society (Poland) and the Comite Mexicano para la Prevencion de la Osteoporosis A.C.

The Family Gala Dinner



IOF President Pierre D. Delmas chats with special invitee Judith Cranford, Executive Director of the National Osteoporosis Foundation, USA

Held at the magnificent waterside 18th century edifice "Esma Sultan Yalisi", the gala dinner was a very special evening for all – and particularly for the six member societies which were honored with awards. A highlight of the evening was also the screening of videos produced by the winners of the same awards in 2002. The videos were impressively professional and gave a good overview of the winning projects.

Social program

After the second workshop sessions held on the morning of September 6, delegates were treated to a wonderful afternoon of sightseeing, a fantastic boat cruise on the Bosphorus and an elegant dinner at the romantic "Maiden Tower" island. Delegates not only appreciated the opportunity to see magical Istanbul, they were also happy to have some time for relaxed discussion in what is a very "action-packed" 3-day conference. IOF thanks Aventis of Turkey which, as a local platinum sponsor, kindly made this unforgettable day possible.

Plenary Session

The final day of the IOF-WWC was devoted to plenary lectures which included panel reports on the latest research developments of interest to patient societies, as well as workshop summaries and, for the first time, award presentations.

IOF Roche-GSK Communication Grants presentations



Sharma Shushil of the Arthritis Foundation of India Trust wins the IOF Roche-GSK Communication Grant

After workshop leaders had summarized their workshops of the previous days, presenters Daniel Navid, Helen Walicka of Roche and Janet Kettels of GlaxoSmithKline announced the three winners of the new communication grants which receive US\$10,000 each for their creative communications activities (and an original ceramic sculpture). The winners of the 2003 awards announced in Istanbul were the Bundesselbsthilfeverband für Osteoporose e.v. (BfO), the Sociedade Brasileira de Pacientes com Osteoporose (SOBRAPCO) and the Arthritis Foundation of India Trust.

Panel scientific reports

Professor Peter Burkhardt chaired this session and spoke on the **latest developments in nutrition**, including new insights about the role of dairy products in young people and adults and the importance of phosphorus, protein and vitamins D and K.

Professor Refik Tanakol of the Turkish Society of Endocrinology and Metabolism offered a thorough overview of the latest data on **osteoporosis in men**. New evidence suggests that osteoporosis in men is hugely underestimated, that at around the age of 80 men lose more bone than women, and that the outcome of osteoporotic fractures in men is more severe than in women



The scientific panel offered participants a valuable overview of latest developments

Hormone replacement therapy, currently a "hot" topic, was reviewed in an excellent presentation by Dr. Efteem Azar, gynecologist and representative of the Jordanian Osteoporosis Prevention Society. As a result of new studies on large numbers of women, the role of HRT has been re-evaluated. Dr. Azar showed that, while HRT is still an option for the treatment of menopausal symptoms in some women, there are other effective non-hormonal therapies available for the treatment of osteoporosis. [See Dr. Azar's presentation on HRT](#) (PDF, 92 KB)

Prof. Jean-Yves Reginster reviewed the cost **burden of osteoporosis** based on new studies. He emphasized that while the direct costs have been calculated, the indirect costs (whether those of human suffering, work days lost of both the patient and family, loss of independence resulting in nursing home care etc) are rarely calculated.

In his presentation on **new treatments**, IOF President Pierre D. Delmas, outlined the available treatments, their strengths and methods of action. New treatments that will soon be available include parathyroid hormone and strontium ranelate.

Conference closure and thanks to hosts

After a brief question and answer period, a very successful three-day conference came to an end. IOF CEO Daniel Navid and delegates thanked Dr. Gulseren Akyuz and her colleagues for their warm hospitality and organization.

Thanks were also given to the international sponsors – Lilly, Novartis and MSD – and local sponsors – Aventis, Roche, Lilly, MSD and Novartis (listed in order of level of support), for the generous support without which the conference would not have been possible.