

# 10th IOF World Wide Conference of Osteoporosis Patient Societies

September 27- 30, 2005, Bangkok, Thailand

Held for the first time in Asia, the biennial IOF World Wide Conference of Osteoporosis Patient Societies (IOF-WWC) took place from September 27- 30, 2005 in Bangkok, Thailand. Some 200 delegates from patient-oriented societies in 60 countries attended the three-day conference.



In conjunction with the conference, IOF held a **seminar for Asian journalists** and a special **'Beauties and the Bones' press conference** at which seven beauty queens from four continents appealed to girls and young women to care for their bone health as a first step towards preventing osteoporosis later in life. The women, from Australia, Austria, Panama, Thailand, Turkey and Venezuela, urged women of all ages to take responsibility for their bone health, and to recognize that while beauty is partly physical it is also made up of inner beauty that includes respecting one's health and behavior.

Prior to the conference, IOF also held communication training workshops for a select number of delegates. The participants learned valuable interview and presentation techniques with professional instructors on a one-on-one basis



## Opening Ceremony



It was a great honor to have **Her Royal Highness Princess Galyani Vadhana KromLuang Naradhiwas Rajanagarindra** preside over the official opening of the conference on the evening of September 28th. Following welcome speeches by **Prof. Khungying Kobchitt Limpaphayom**, president of the Thailand Osteoporosis Foundation and IOF Board Member **Dr. Ghassan Maalouf**, Her Royal Highness spoke eloquently to the delegates, praising the work of the patient societies in their fight against osteoporosis in Thailand and throughout the world. Her Royal Highness also presented a token of appreciation to each of the supporters of the IOF WWC and to representatives of IOF and the Thai Osteoporosis Foundation.

## First Plenary Session



The official program began with a welcome speech by **IOF Chief Executive Officer Daniel Navid** who noted, "It is particularly important that we are meeting in Bangkok because the number of people suffering from osteoporosis is growing fastest in the Asian region – by 2050 one out of every two hip fractures worldwide will occur in Asia."

**Dr. Khungying Kobchitt Limpaphayom** welcomed participants on behalf of the Thailand Osteoporosis Foundation. In her speech Dr. Kobchitt pointed out that osteoporosis affects not only the health and quality of life of the patient, but also of the family and society. She emphasized that the problems posed by osteoporosis will only be solved when there is greater understanding and awareness of osteoporosis and unity among all medical and patient organizations in fighting the disease.

**Dr. Istvan Marton**, chair of the IOF's Subcommittee of Osteoporosis Patient Societies, reminded the audience that patient societies play an important role in fighting osteoporosis and that it is important to keep in mind that "you are the ambassadors of the patients that we are serving".



**Dr. Borworn Ngamsiriudom**, deputy director general of the Thai Department of Health of the Ministry of Public Health, spoke about the steps that his government is taking to improve the diagnosis and treatment of people at risk of osteoporosis in the country. He outlined the health departments existing exercise and nutrition programs as well as the focus on high risk groups such as post-menopausal women and the elderly.



In an inspiring keynote address entitled "Thinking out of the box and ahead of the curve", **Mechai Viravaidya**, chairman of the Population and Community Development Association, urged IOF members to be courageous and creative in their efforts to change health care policies. Using examples from successful campaigns to promote family planning in Thailand, Mr. Viravaidya suggested that osteoporosis patient societies should consider taking unorthodox approaches to improving the awareness and management of the disease. He underlined that solutions which are suitable for western industrialized countries are not necessarily those best suited to developing countries – tantamount to "trying to find your way in Bangkok with a map of London".

## Open Mike Presentations

Open mike presentations were given by four speakers. The first two speakers – both prominent women who are personally dedicated to the osteoporosis patient movement in Thailand – spoke about the evolution of a medical society into a patient-oriented organization. **Mrs. M.R. Malinee Chakrabandhu** (*below left*), president of the TOPF-affiliated patient society, especially stressed the importance of reaching people in villages to improve understanding of the disease. **Mrs. Pensri Kiengsiri** (*below right*), a well-known writer and lecturer, reminded the participants that people from all walks of life are needed to successfully run a patient society. On a final note, Mrs. Kiengsiri added that "We care a great deal about our figures, but not sufficiently about our bones – from now on lets think more of our bones and less of our figures".



**Dr. Joan Levin**, president of FOSEMO of Panama (*above left*), discussed the power of celebrities to open doors to public and government recognition and well as sponsorship. Dr. Levin outlined the steps a society should take in order to get celebrity support and showed how the support of FOSEMO patron Miss Justin Pasek (Miss Universe 2002) and well-known Latino singer and songwriter Erika Ender has been instrumental for FOSEMO's recent campaign successes,. She noted that that clear goals, strategies and communication are essential because celebrities may be willing, but they "don't know they can help until you tell them how".

'Achieving big results with limited resources' was the title of the presentation given by **Prof. Lidia Koeva** of the Association Women Without Osteoporosis of Bulgaria. She outlined how this small society has achieved results in regard to partial reimbursement policy before first fracture – a goal not yet been achieved in many wealthier countries. Prof. Koeva stated that close collaboration with IOF, and use of the EU 'Action Plan' plan published by IOF, were instrumental in achieving policy change in her country.

## The Workshops

Delegates subsequently took part in six concurrent workshops covering: **advertising, patient support, exercise, growth in your society, lobbying and special events/major donors**. The workshops, designed to encourage interaction and communication among participants, were held both on the 28th and the 29th to allow each delegate to attend two different workshops. A final summary report of the workshop results was

presented to all attendees on the final morning of the conference. Workshop material, presentations and result summaries will be available to members on the IOF members only/resources section of the IOF website as they become available.



## Second Plenary Session

After the workshop summary presentations, the second plenary session featured talks on the latest developments in science given by members of IOF's board of directors.

IOF General Secretary **Prof. Jean-Yves Reginster** presented a glimpse of exciting new perspectives in osteoporosis management – including promising new drugs that are in the pipeline. He stated, "Every year there are better, safer, medications in terms of anti-fracture efficacy". **Prof. Helmut Minne**, IOF chair of the CNS and author of IOF's new popular report 'Move it or Lose it', gave an overview of the role of exercise in bone health. He stressed the importance of improving muscle function and the related role of vitamin D. Most importantly, although not as plentiful as drug studies, new studies on exercise are proving that it is an important aspect of bone health and osteoporosis therapy. IOF Board Member **Dr. Ghassan Maalouf**, who is the Chair of the vertebral fracture working group within IOF, spoke about the severity of these fractures and emphasized that vertebral fracture itself is an independent risk factor for future fractures, even within a normal BMD range.





Delegates were also briefed on plans for World Osteoporosis Day 2005, which will be held globally on October 20. The theme is "Move it or Lose it", the role of exercise in building strong bones and reducing fracture risks. **Paul Sochaczewski** presented some highlights of WOD 2005, including the **"Move it or Lose it" popular report**, eight 30-second Public Service Announcements featuring leading global personalities and celebrities, and a new **osteoporosis song and music video**, produced in Spanish and English by singer/songwriter Erika Ender "Un Cuerpo Sano/A Health Body".

## Award presentations

A highlight of the WWC was the award ceremony in which IOF grants valued at US\$ 126,000 were presented to eleven national osteoporosis societies. Julia Gallagher, one of the award winners stated, "To receive international recognition for a local initiative will add enormous credibility to our efforts at the national level". This sentiment was shared by all the winners, most of whom noted that the recognition afforded by the award was just as important as the financial support.

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The [IOF-Novartis Osteoporosis Education Grants](#), five grants of US\$10,000 each for the most imaginative education projects, were awarded to the societies by Roche representative Stefan Korte and IOF Board Member Dr. Ghassan Maalouf. The winners were the Indonesian Osteoporosis Society (**Indonesia**) for their project "PEROSI campaign"; Endocrinology and Metabolism Research Center (**Iran**) for the project "Constructing stronger bones" ; Jordanian Osteoporosis Prevention Society (**Jordan**) for their project "Be good to your bones" ; Fundacion de Osteoporosis y Enfermedades Metabolicas Oseas (**Panama**) for their project "My bank of bones" ; and the Taiwanese Osteoporosis Association (**Taiwan**) for their project "Public education materials".



The [IOF-Roche GSK Communications Grants](#) are three grants of US\$10,000 each for creative communications campaigns. The presentations were made by **Christine Phelan** of GSK, **Stefanos Tsamousis** of Roche and **Dr. Istvan Marton**, Head of IOF's Patient Society Sub Committee. The winners were the Norwegian Osteoporosis Society (**Norway**) for their project "Nordic walking"; FHOEMO (**Spain**) for their project "Spanish campaign on osteoporosis" and the Uruguayan Rheumatology Society (**Uruguay**) for their project "Advertising for prevention of osteoporosis".



The [IOF-Amgen Health Professionals Awareness Grants](#) were presented by **Neil Hughes** of Amgen and IOF General Secretary **Jean-Yves Reginster**. Three grants of US\$10,000 each for innovative ways to communicate with health professionals were awarded to Beinvernd (**Iceland**) for their project "Osteoporosis concerns us all!"; the Indian Society of Bone and Mineral Research (**India**) for their project "National Bone Health Quiz" and Osteoporosis New Zealand (**New Zealand**) for their project "Osteoporosis management guidelines".



The [IOF Linda Edwards Memorial Grant](#) is a grant of Swiss francs 20,000 given by IOF to a dynamic young member society in memory of the late Linda Edwards, one of the founders of the global osteoporosis patients movement. The award was presented to the Slovene Osteoporosis Patient Society (**Slovenia**) by Prof. Helmut Minne, chair of the CNS.

## Social Program



Social interaction among participants is a much valued part of the biennial patient society conferences. The conferences give the delegates a unique opportunity to informally exchange ideas and discuss common problems. As a result, commonly overheard statements during meals and coffee breaks include "I didn't know you had the same problem" and "that's an interesting idea". In Bangkok, participants were treated to a wonderful family dinner featuring classical Thai music and dancing as well as a traditional puppet show. They also enjoyed a memorable afternoon tour of the Royal Grand Palace and a beautiful dinner cruise on the Chao Phya River.

On behalf of all participants, IOF thanks the Thai Osteoporosis Foundation and the Royal Orchid Sheraton for the warm hospitality and ATOP for their excellent organization of the social program.

## Thanks to sponsors

IOF thanks the many sponsors for their valuable unrestricted financial support which made this memorable conference possible:

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