



## IOF WWC 2009

**Organization** in cooperation with the China Health Promotion Foundation (CHPF)

**Venue** Beijing International Hotel – Beijing, China



## IOF Worldwide Conference of Osteoporosis Patient Societies

SEPTEMBER 22 - 25, 2009 • BEIJING, CHINA



Over 125 participants from 48 countries

Dynamic presentations  
Latest science presented

New ways to sell the prevention message covered

Innovative media campaigns featured

New health professional grants awarded

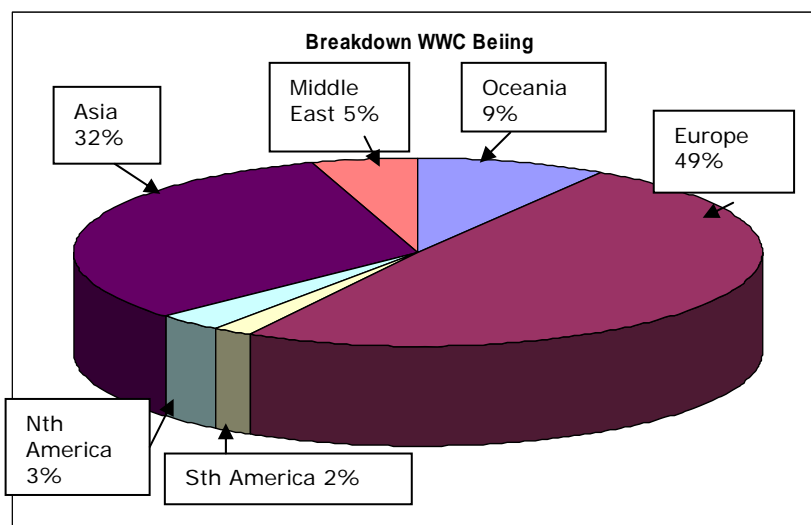
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Participation breakdown:



## Program Highlights

- Media Launch of Asian Audit - *Tuesday September 22*
- CNS Regional Asian Meeting - *largest ever attendance*

### Key note presentation: *The Power of Patient Societies*

Naseema Sparks (Australia)

A dynamic presentation from one of Australia's leading female business identities. Naseema is the previous MD of M & C Saatchi, one of the world's leading advertising agencies and is a non-executive director of several major corporate and NFP entities including Osteoporosis Australia.

Her presentation covered the role of patient societies in effecting change, the power of individual voices and group voices advocating for a single cause. She also covered the shifting bases of power over the last 2 decades and gave some powerful case studies, in and out of the bone world;

- HIV AIDS actions – from fear to understanding
- James Hardie Australia – company strength to social justice
- Women without osteoporosis – treatment to prevention



She concluded with the importance of patient societies in our dynamic world and common pitfalls and new opportunities. *(All presentations are available on the IOF website).*

## Workshops

### - Reaching Primary Health Care Professionals

*Leaders: Joon Kiong Lee (Malaysia) & Suely Roitman (Brazil)*

The workshop gave various options to reach primary health care professionals, taking into consideration the countries specifications and made a distinction between primary medical HCP and primary allied HCP.

The motto of this session was *'train, educate, and equip to fight osteoporosis'*

### - Influencing policy Makers and working with Governments

*Leaders: Famida Jiwa (Canada) & Ambrish Mithal (India)*

A questionnaire was circulated to CNS a few months ago to gain a better understanding of the level of expertise and experience of Patient Societies around advocacy.

The workshop explored ways to develop an effective advocacy strategy (key message development, development of tools, development of one "ask").

Tips and recommendations to develop effective strategy:

- What is it that you would want to say to decision makers about this issue?
- What would you ask your decision makers in your country to do?
- What tools would you use specifically in each county in order to deliver the key messages and one 'ask'?
- Have a patient story *at the ready!*(3 min max)



### - Selling the message about fracture prevention

*Leaders: Gabriele Suppan (Austria) & Melita Daru (Australia)*

Various approaches to a successful campaign:

Select the target group, la portée (short or long term) and build a strong and appropriate key messages.

A few suggestions to IOF:

- Survey about ideas of messages and campaigns of CNS
- Global branding – building for World Osteoporosis Day
- Framework for campaigns for key target groups

### - Generating media for your cause

*Leaders: Tatiana Drakopoulou (Greece) & Sabine Habicht (Germany)*

The workshop reviewed the following:

- presentation of all media types
- choosing the best form of media for your purpose
- integrate ideas
- live exercise: planning a media campaign / tips



Tips and recommendations on choosing the right media for you:

- Keep a good-standing relationship with media
- Work with negative media
- Avoid media mistakes
- Don't focus only one element of the concept
- Involve all the important media
- Combine all media forms for best result
- Be creative

- **Fractures and Falls – Bringing the messages together**

*Leaders: Anthony Kwok (Hong Kong) & Siok Bee Chionh (Singapore)*

Review the important causes of falls to address appropriate interventions

Recommendations to IOF:

- Facilitate education of patients and public on importance of falls and fall prevention through IOF website, educational pamphlets in different languages, videos
- Facilitate education of health professionals on importance of falls, fall management and prevention through up to date slides to use in teaching doctors and other health professionals
- Encourage health professionals to give talks to architects and urban planners

- **Building Capacity and raising funds for your organization**

*Leaders: Louisa Zhang (Singapore) & Robi Sulzbacher (Switzerland)*

Covered; 1. the most effective ways to build capacity based on some concrete case studies and 2. simple, effective strategies for small, medium and large organizations to raise funds.

Things to remember:

- perform regular analyses and accept that things change
- implement solutions to existing problems
- Set short-, medium-, and long-term goals
- New ideas to raise funds – be innovative
- Very important message (Fracture free = growing old gracefully / provide an image to your donor / Stand Tall vs wheelchair bound / Social responsibility of donor)

## Bright ideas

The bright ideas session was initiated at the WWC 2007 held in Miami. It is a show case of creative and innovative activities that have been developed by CNS members throughout the year.

There are 3 categories for submission:

1. communications
2. celebrities & special events
3. Jackpot.



- ✓ Turkish Osteoporosis Patient Society - *Project name Right now for your bones*
- ✓ Osteoporosis Canada - *Project name Breaking barriers, not Bones*
- ✓ Bundesselbsthilfeverband für Osteoporose - *Project name Poster series – advertising & education*
- ✓ Osteoporosis New Zealand - *Project name How good are you? Measure your performance*
- ✓ Hungarian Osteoporosis Patient Association - *Project name Funny role-playing....*
- ✓ FHOEMO – *Project name Osteoporosis prevention campaign*
- ✓ Osteoporosis Society (Singapore) - *Project name Orchard Mile Run*
- ✓ Turkish Osteoporosis Society - *Project name A special tree for you!*
- ✓ Irish Osteoporosis Society – *Project name 3-a-Day campaign*
- ✓ Perwatusi (Indonesia) – *Project name Talk Show with Miss Indonesia-Universe*
- ✓ Arthritis Foundation of India – *Project name Signature campaign*



### Scientific session – all the latest data from the scientific bone front!

- The Asian Audit: a picture of osteoporosis in Asia – Dr Ambrish Mithal
- Recent insights into the pathophysiology and treatment of osteoporosis – Prof Cyrus Cooper
- The Orthopaedic Surgeon & Fractures prevention – Dr Suthorn Bavonratanavech



### Osteolink launch

Judy Stenmark and Cyrus Cooper gave a presentation of the results of the extensive survey undertaken throughout Europe and Australia to investigate the physician – patient communication dynamic and assess perceptions on the management of osteoporosis.

Key findings from the survey:

- ✓ Patients believe they are better informed about their osteoporosis than the data reveal
- ✓ Patients are significantly more concerned about the impact osteoporosis has on their quality of life than physician believe
- ✓ Patients want easy to understand tools and greater interaction with their physician and other patients to help manage their osteoporosis



- ✓ Physicians support patient programmes and are eager for tools to help communicate with their patients about their osteoporosis.

They discussed the roll-out of OsteoLink across Europe and Australia in 2009-2010. The immediate next steps being the creation of an OsteoLink scientific committee chaired by René Rizzoli and the local country task forces established in Germany, Switzerland, Austria and Sweden. An update from the first launch countries will be made public at the IOF WCO/ECCEO10 in Florence, Italy – May 5-8, 2010.

## Awards

**The IOF-Linda Edwards Memorial Award** - This unrestricted grant (valued 20,000 CHF) is intended to help osteoporosis societies carry out their work to increase awareness and prevention of osteoporosis and to improve the care of patients at the national level. The winning society, selected by an IOF jury, must be a CNS member and exemplify Linda's spirit ("thinking big", practical and effective projects, devoted staff, imagination, scientific credibility). The society should also have a financial need for the award, show a likelihood of success, and agree to report on how the funds were used by the society.

*2009 IOF Linda Edwards Memorial Award winner is:*

- ✓ The Arthritis Foundation of India Trust
- ✓



**The IOF-Amgen Health Professional Grants** – in 2009 five grants of US\$10,000 each - will support innovative and cost effective projects by IOF member societies. The projects should be directed at health professionals and aim to inform why osteoporosis is so important, explain diagnostic and treatment options and develop innovative and east-to-use tools to raise awareness among doctors.

The winners are:

- ✓ Armenian Osteoporosis Association
- ✓ Aktion Gesunde Knochen – Action for Healthy Bones (Austria)
- ✓ Bulgarian League for the Prevention of Osteoporosis (BLPO)
- ✓ Hungarian Osteoporosis Patient Association (HOPA)
- ✓ Osteoporosis Society Singapore



## Videos and reports from previous award winners (2007 WWC Miami)

All videos will soon be available on IOF web Gallery at:

<http://www.iofbonehealth.org/iof-videos.html>

### *IOF-Linda Edwards Memorial Award*

Hellenic Society of Osteoporosis Patient Support

### *IOF-Novartis Strong Bones Academy Grants*

- Brazil: National Federation of Osteoporosis Patients Associations (FENAPCO).
- Israel: Israeli Foundation for Osteoporosis and Bone Diseases (IFOB)
- Vietnam: Vietnam Rheumatology Association

### *IOF-Roche-GSK Communications Grants*

- China: Chinese Osteoporosis Foundation of Chinese Development Foundation for Science & Technology (COF-CDFST) - CHPF
- Russian Federation: Russian Association on Osteoporosis
- Uruguay: Uruguayan Rheumatology Society

### *IOF-Amgen Health Professionals Awareness Grants*

- France: Groupe de Recherche et d'Informations sur les Ostéoporoses (GRIO)
- Hong Kong: Hong Kong Osteoporosis Foundation
- Italy: Lega Italiana Osteoporosi (LIOS)
- USA: National Osteoporosis Foundation (NOS)
- Venezuela: Sociedad Venezolana de Menopausia y Osteoporosis (SOVEMO)

## Thanks to sponsors

IOF extends a warm thank you to the corporate sponsors who have provided support for the 2009 Worldwide Conference of Osteoporosis Patient Societies, Beijing:

**Gold Sponsors:** Amgen, Eli Lilly, Novartis

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