12th IOF EU Osteoporosis Consultation Panel
and
IOF European Parliament Osteoporosis Interest Group

Wednesday November 7, 2012
Hotel Silken Berlaymont, 11-19 Blvd Charlemagne, Brussels

Meeting Report

Welcome by Prof Juliet Compston, Chair, EU Panel

Address by Anja Weisgerber, MEP, Co-chair, Interest Group
She described her personal interest as her father was diagnosed with osteoporosis before a hip operation, but stressed that it continues to be a problem of under-diagnosis and lack of awareness among politicians. She agreed that an EU document such as the Scorecard is an important tool in addressing best practice in fracture care.
Ms Weisgerber recommended that Horizon 2020, an EU Framework Program for Research and Innovation, be explored by IOF. As well, she suggested that IOF consider partnering with other disease organizations to better prepare and compete for funding competition.
Regrettably, Ms Weisgerber is leaving the Interest Group due to her pregnancy and upcoming plans to run in the national parliamentary elections. Juliet and the members thanked her for her generous contributions to the Interest Group, with best wishes for her future career.

Address by Mary Honeyball, MEP, Co-chair, Interest Group
She suggested many strategies that could strengthen the Scorecard policy efforts in the EU:
• Focus on the economic message, for example that fractures not only carry a high health service cost, but are a burden to employers and employees
• Utilize the strength and dedication of IOF, Panel and Interest Group members
• Develop a strategy for the Scorecard – for example the Horizon 2020 program for research funding
• Lobbying – the Interest Group is key, but requires more members. This is a challenge due to competing interests, but she encouraged putting more pressure on MEPs by local members of this Panel and Societies, both nationally and locally.
• Expand the media profile
• Provide support to the Ministries of Health – what solutions do we have for funding challenges?
• Seek alternate funding outside Pharma
• Utilize the strength and motivation of patients
• Collaborate with chronic disease organizations
As of the deadline, 2/3 of EU members have returned their questionnaire. He strongly encouraged remaining members to complete the information as soon as possible.

Presentation highlights:

- **Scope of the problem**
  - 22 million women and 5.6 million men in the EU have osteoporosis (ref. WHO)
  - In there were 3.5 million new fractures in women and men
    - 390/hour; 9556/day
  - Any strategy to address fractures needs to include wrist and vertebral fractures as well as hip due to their economic and personal costs
    - Direct cost per capita/year : €75 / year all ages
    - Added QALY : €134/year
    - Total: €199/year
  - Heterogeneity is evident in the incidence of OP in the EU

SCOPE: measures

- Background information – prevalence / the size of the problem
- Policy Framework
- Service Provision – DXA, treatment availability, accessibility; national guidelines
- Service Uptake – DXA, treatment uptake, wait times. There is a significant treatment gap shown in the leveling off of usage trends, and in the reported 3 million women that stopped their osteoporosis treatment.
- Country data has been compiled, ranked and graphed to measure
  - Prevalence of hip/spine fracture vs % of population > 50 yrs
  - DXA units/million population
  - Uptake of FRAX/million population
  - Service uptake that assesses the treatment gap in women

An all-EU summary graph has been prepared to illustrate overall SCOPE elements, and assigned red, green, yellow to illustrate relative ranking of large, moderate, less problems.

The final SCOPE results are anticipated at the ECCEO meeting in April in Rome, with research and data collecting still in progress.

**Prof Kristina Åkesson – Capture the Fracture**

Background of the consequences of the secondary fracture problem were reviewed – prevalence, quality of life and economic consequences of fracture

- The high morbidity associated with typical OP fractures is shown vs morbidity attributed to ageing alone
- Healthcare systems around the world are failing to capture the first fracture and prevent second fracture.

A proven solution is the coordinator-based, post fracture model of care – or FLS – Fracture Liaison Service. Several models have been established in Canada, US, UK, Australia and Europe showing that a dedicated coordinator working in parallel with other healthcare team members in the identification, investigation, and intervention for both in and outpatient fracture patients can break the cycle.

Capture the Fracture has established as a Best Practice Framework of recognized and established standards of care. A recognition program that measures intervention systems is being developed, including an online interactive map of current global programs, guides and toolkits, a grant and mentorship program, marketing and communication, and an international coalition of partners has been established.

The Best Practice Framework includes 14 standards, each with 3 levels of achievement (gold, bronze, silver). The beta version of the interactive map platform for sharing and monitoring information is expected to be available soon.
Discussion was opened up to meeting participants – Highlights:

SCOPE:
- All those who submitted data will be given the chance to review their data and charts prior to finalization
- Individual country supplements will be provided as background to the comprehensive summaries, based on quality information provided
- Each country will be responsible for interpreting their own data
- Each country needs to make comparisons of their own data with other countries (to shame and celebrate)
- Trending of bisphosphonate uptake has leveled off and decreased since 2009. Possible explanations
  - economic restrictions to filling prescriptions;
  - large generic influx to which Prof Kanis explained should not have been a contributor when compared to statins which caused a significant uptake
  - contradictory articles and media coverage of BP side effects. A common message is required to put this information into perspective
  - The fracture working group needs to produce a slide kit for orthopedic surgeons and dentists re BP side effects – in response to their discontinuation of treatment
- Handouts and IOF downloads are necessary for politicians and policy makers – the group supported a simple, user friendly 1-pager that could be supplemented by a resource document

Capture the Fracture:
- Prof Akesson explained that the program with FLS has been shown to be cost effective, despite initial costs. The program encourages these costs to be established at the front end and that long term benefits be acknowledged
- The program should be targeting the high risk for fracture patients
- Cthef offers a business model for healthcare payers
- Targets should be set, with monetary rewards for performance – as established in other medical models
- The Cthef program could be interpreted as ‘pushing the need for more drug treatment’. There is a need to understand what portion of the economic burden is due to pharmacology

Other:
- Most attendees claimed national guidelines were available – Prof Kanis encouraged all to submit these to the IOF website (Laura Mistelli or Judy Stenmark)
- Patients represent a strong voice. Prof Kanis reminded everyone that the free IOF membership could not only represent societies but potential of millions of people

Judy Stenmark - World Osteoporosis Day 2012 Activities

The themes of this year’s WOD are Capture the Fracture and Stop at One – make your first break your last. The Stop At One theme provides a consistent message to patients, the public, healthcare professionals, the media and policy makers to break the fracture cycle. The problem of fractures and their consequences are common and costly in economic and human terms with decreased quality of life and impaired mobility and independence.

The Capture the Fracture Report has been made available in 7 languages on the IOF website and [www.worldosteoporosisday.org](http://www.worldosteoporosisday.org). Outreach activities have been extensive – with media releases, press conferences; events and campaigns worldwide. The global media impact with thousands of print and online articles with global circulation in the millions.

Member presentations of WOD activities to support policy:
- Roman Lorenc, Poland, presented on a Vitamin D symposium. 560 attendees from 18 countries met in Brussels to establish a consensus on many benchmarks for Vitamin D – from therapeutic daily recommendations to Vit D blood levels. A final document is in progress, but a consensus has not yet been reached
- Helena Salminen, Sweden, presented the recently developed national osteoporosis and musculoskeletal guidelines
• Eugen Nagy, Slovakia, reported on 3 activities that were organized for WOD 2012
  ▪ Press Conference in Bratislava, organized by Slovak Society Chairman Prof Juraj Payer, a member of the Panel
  ▪ National Council of the Slovak Republic event to raise awareness of fractures
  ▪ Doors Open day with osteologists measuring and assessing DEXA throughout Slovakia

**Donna Spafford** – Cyprus Musculoskeletal Health Roundtable Report
The first IOF Roundtable event held in conjunction with an EU Presidency took place in September, a collaboration between IOF and the Cyprus Society for Osteoporosis and Musculoskeletal Disorders. Among the objectives for the event were

• Visibility for IOF within the Cyprus presidency
• Promote awareness and burden of fractures at the level of the European Commission and national level in Cyprus
• Strengthen mutual goals of IOF and European Year for Active Ageing 2012
• Promote and disseminate Capture the Fracture program
• Utilize the EU policy Scorecard initiative to strengthen advocacy activities in the EU and Cyprus

Extensive outreach through radio, television, press and social media was coordinated by the Society and IOF – resulting in more than 130 attendees for this successful event.

The Cyprus Minister of Health gave an address, his participation lending support to the event. Future collaborations between IOF and active EU presidencies are being considered when osteoporosis and musculoskeletal diseases can be incorporated as a health priority issue within the presidency.

**Attendees:**
Prof Juliet Compston, Panel Chair
Mary Honeyball, MEP, Interest Group Co-chair
Anja Weisgerber, MEP, Interest Group Co-chair
Prof John Kanis, IOF President
Prof Kristina Åkesson, Chair, Capture the Fracture Working Group
Judy Stenmark, IOF CEO
Donna Spafford, IOF Policy Consultant
Prof Gerold Holzer, Austria
Ms Gabriele Suppan, Austria
Dr Pernille Hermann, Denmark
Dr Toomas Tein, Estonia
Dr Katre Maasalu, Estonia
Dr Olli Simonen, Finland
Prof Thierry Thomas, France
Prof Istvan Marton, Hungary
Prof Moira O’Brien, Ireland
Ms Michele O’Brien, Ireland
Dr Marija Tamulaitiene, Lithuania
Dr Simone Steil, Luxembourg
Prof Roman Lorenc, Poland
Dr Salvina Mihalcea, Romania
Dr Eugen Nagy, Slovakia
Dr Dusa Zore, Slovenia
Prof Jorge Cannata-Andia, Spain
Ms Caroline Akerhielm, Sweden
Dr Helena Salminen, Sweden