

**EUROPEAN UNION OSTEOPOROSIS CONSULTATION PANEL
MEETING REPORT
APRIL 16, 2008, BRUSSELS**

The 6th European Union Osteoporosis Consultation Panel meeting was held in Brussels on April 16, 2008.

Consultation Panel members have spent the past several months collecting data on the state of osteoporosis in their country in preparation of the EU Osteoporosis Audit Report. Today participants from all 27 EU member states joined with European Parliament Osteoporosis Interest Group members and invited speakers to preview early data in preparation for the October 14 launch of the report in Brussels on the occasion of World Osteoporosis Day.

Consultation Panel members, MEPs, invited guests and speakers were welcomed by Donna Spafford, IOF Senior Policy Consultant. Prof John Kanis was warmly acknowledged by all as the newly elected president of IOF.



As European Parliament Osteoporosis Interest Group co-chair, Mary Honeyball, MEP UK (*right in photo*) welcomed Panel members to Brussels, and expressed interest in hearing more about the Audit Report. Mrs Honeyball acknowledged the MEP meeting in Strasbourg which was held in October 2007, expressing delight in having new MEPs join the Interest Group.

Mrs Honeyball noted that there remains a “great difficulty, especially for the elderly, in integrating osteoporosis as a health care priority in Europe. Early Audit Report data indicates that there is still a level of ignorance of osteoporosis among the EU, with only 9 of 27 EU members having made osteoporosis a priority. MEPs need to do more, and a dialogue with Panel members is an excellent foundation, resulting in useful discussion and awareness-raising.”

Angelika Niebler, MEP Germany, co-chair of the EP Osteoporosis Interest Group (*left in photo above*), acknowledged that this is the 6th EU Consultation Panel meeting, a great tradition that she’s happy to be part of. Mrs Niebler cited a recent German study of young people who were asked to rank various qualities in life that were important to them. The top 3 were friendship, partnerships, and family, followed by personal responsibility, contacts, independence, security and ambition, with health in 11th place.

While recognizing that the top 3 are critical as a foundation, Mrs Niebler hoped "that a healthy lifestyle would be a more important quality but that often it is only once an illness is suffered that one realizes how important health is." Mrs Niebler emphasized that raising awareness is necessary to prevent losing other qualities of life and to ensure friendship, partnership and family remain important. In this respect, Mrs Niebler hoped that the collaborative work of the Interest Group and Consultation Panel would raise the standard of osteoporosis in the EU.



EU Osteoporosis Consultation Panel Chair Prof.

Juliet Compston thanked the staff of IOF and the Consultation Panel members for their work this year on the Audit Report. Prof. Compston highlighted the fact that all 27 member states are now represented in the Panel.

Prof. Compston recognized Prof. John Kanis once again, stating the need to integrate FRAX™ tool into practice, and indicating that the challenge will

be in setting intervention thresholds which is important to its success. Prof. Compston also stressed that we can easily compete with other diseases in regard to the disability it causes and the cost. "We have the knowledge, we have the tools, now we need integration", she stated.

After reviewing the 8 Recommendation from 1998, Prof Compston stressed the importance of hip fracture reporting, and the access to bone densitometry which is still under-utilized in many countries.

The Audit Report, which will be titled "Osteoporosis in the European Union in 2008: Ten years of progress and ongoing challenges" will be finalized over the next few months, but early data shows that:

- While in 2001 not one of the EU member states supported osteoporosis as a healthcare priority, this report shows that only 8 of 27 have declared its importance, showing that national governments still need to be persuaded about the importance of osteoporosis.
- The increase in hip fracture incidence, increased in many cases from earlier reports, may tell us that fractures are on the rise, but also that our collection of data has improved.
- DXA: A 2005 publication by Kanis et al showed that the recommended number of DXA scanners per 1 million population is 10.9. More than half the EU states still fall below this and, as Prof. Compston noted it is not always a matter of how many units there are, but a need for better distribution, with many areas still under-resourced.
- The cost of DXA is quite varied, often expensive and with limited reimbursement, access is restricted.

- Treatment: the same applies, while most countries have approved best medicines, there are restrictions for access, or limited reimbursement, again resulting in limited use. This is most significant in the case of high risk patients and the prevention of the first fracture.

While this is only a preview of the final report due out in October, it indicates some of the areas of success as well as care gaps that still need to be addressed. Our objectives remain improving the availability and reimbursement of bone densitometry scans and reimbursement of proven therapies for people at risk of osteoporosis before the first fracture.



“We’re at a crossroads for policy work in Europe” began **IOF CEO Dan Navid**’s presentation on plans for WOD 2008. “We have the scientific information we need, gains have been made, but challenges remain as we’ve seen in our Audit preview”.

He went on to explain that IOF’s efforts aim to 1) show osteoporosis is a major health problem, comparable to other diseases, 2) show that governments can reduce costs by preventing the first fracture, 3) improve national competitiveness by working longer number of years, and 4) recognize we represent a political force with IOF member societies in 89 countries representing 5.33 billion voters, taxpayers and consumers.

WOD 2008’s theme is Stand Tall, Speak Out For Your Bones! The global WOD launch will be held in the Renaissance Hotel in Brussels on October 14. In addition to the formal launch of the EU Osteoporosis Audit Report, a European Women Leaders Roundtable will be held which is expected to attract media attention. Other regional WOD events will be held in Rio de Janeiro and Beijing.

Mr Navid indicated that IOF expects this theme to generate enthusiasm for advocacy and the mobilization of scientific, political and patient populations. To aid in these efforts, IOF will provide the following tools:

- A thematic report written by Prof. Juliet Compston
- A simplified version of the thematic report in the form of a public leaflet
- 6 posters
- To emphasize height loss associated with osteoporotic fractures, measuring tapes and rulers will be produced

Mr Navid encouraged political action through briefing political candidates, questioning political candidates, talking to political parties, posing parliamentary questions, letter writing campaigns, blogs, public forums, and by encouraging other creative ideas among IOF Committee of National Society (CNS) members.

Mr Navid concluded his presentation with suggestions for carrying advocacy messages:

- Essential to have data, statistics and economic cost
- Add the human story
- Recognize we represent a powerful political force of taxpayers and voters
- Develop a clear, specific goal
- Find a "voice" that is comfortable and appropriate
- Have the courage to be creative and to go outside our normal comfort zone

Developing a policy document is only the first step – it is essential to create the right message, deliver to the right people and follow up with updates and reminders. How does one's message stand out from everyone else who knocks on the door of our local, national or EU politicians?



A dialogue, “From Audit to Policy”, was held between Consultation Panel member **Mrs Dusa Hlade-Zore, president of the Slovene Osteoporosis Patient Society** (*left*), and her European Parliament Interest Group counterpart, **Mrs Mojca Drcar Murko, MEP** (*right*).

Mrs Hlade-Zore has been very successful in building and expanding the osteoporosis society, but has also achieved results in building solid relationships with politicians, scientific communities, and funding partners. What worked for her? Keeping it simple, staying optimistic, and identifying the right person for the job.

Mrs Hlade-Zore's sources for delivering the messages are the media, newspapers, friends, pharmaceutical industry, using all methods of communication (email, phone, written letters), and building strong relationships with assistants. Her motto is “the more doors you knock on, the more will open!” In fact, when asked for an example of an unsuccessful meeting, Mrs Hlade-Zore replied that the only bad meeting was no meeting! Preparing her society's volunteers to continue this work was enhanced when they received the IOF Linda Edwards Memorial Award in 2004, using their grant to train volunteers in communication skills: 1) set priorities, 2) respect meeting time and 3) use limited but focused materials.

Mrs Mojca Drcar Murko, MEP has been interested in osteoporosis since joining the Parliament, when she decided to focus on public health and food safety issues. This included overlapping interests in promotion of healthy lifestyles to reduce osteoporosis and other diseases. Her personal connection to osteoporosis began with her mother's condition, where diagnosis came too late to help. Responding to public opinion, and

continuing to raise health awareness, she has been active in promoting “health literacy”. With that, reducing health illiteracy to increase the capacity of individuals to be better informed, gain understanding of health issues, and avoid misleading information – all of which will improve the management of disease.

Mrs Murko explained that data supports the fact that health illiteracy results in increased sick days, more hospital time, and mistreatment all creating more healthcare costs among other things. She acknowledged that the osteoporosis society is one of the most active NGOs in Slovenia thanks to the efforts of Dusa Hlada-Zore. When a question from the audience asked how an EU MEP can influence national health policy, Mrs Murko responded that this may not happen directly, and that it depended on the MEP and how they respond to the demands of their public.

Mrs Murko then explained the process for moving any health policy document through the Parliamentary system. It must include 1) a written declaration of not more than 1 page with 2-3 key points, 2) be signed by other MEPs, 3) be supported by more than half of all MEPs, 4) at this point, the EU Commission is obliged to respond, and 5) the document then becomes a powerful policy tool.



Consultation Panel member Prof Milan Bayer explained that there are 2 osteoporosis societies in the Czech Republic: the Czech Society for Metabolic Skeletal Diseases (SMOS), a professional society with more than 200 physicians, and the League Against Osteoporosis: a patient society with very few members.

In an effort to create a more effective body to influence key health policy officials, the Czech National Osteoporosis Forum (CNFO) was formed in the spring of 2005. This umbrella organisation has a wide membership of osteoporosis stakeholders (scientific society, patient society, pharmaceutical industry, insurance companies, politicians) and, importantly, is chaired by Dr. Milan Cbernoch, MEP.

Since 2005 several activities have been achieved in the Czech Republic: 1) many successful press conferences to advance policy issue through journalists, 2) an information phone line installed, 3) a workshop for the Chamber of Deputies, including bone density scanning, 4) video clips of osteoporosis installed in the waiting rooms of GPs and gynecologists, 5) a poster with the former first lady, Mrs Havel, 6) WOD events. The positive outcome of these activities is reflected in improved knowledge of osteoporosis. However, this has not resulted in a change in health policy. Despite a willingness to pay for prevention of fractures there is no money to support this.

Prof John Kanis presented on the recently released FRAX™ tool: An update on the 10-year fracture risk, explaining that our current diagnosis of osteoporosis is made on the basis of bone mineral density (BMD). The relationship between the osteoporotic fracture rate and BMD is well established.



However, BMD alone is not optimal for the detection of those at risk of fracture. Women with the same BMD show a dramatically different fracture rate depending on their age and other risk factors. It has become clear that we need to be able to identify risk factors that are easily assessed by primary care physicians in order to better assess their patients.

The FRAX™ tool has been developed by studying population based cohorts from Europe, Australia, North America and Asia as a platform to assess risk factors and the probability of someone developing a fracture. While risk factors are determined largely by location and race, fracture data is available in only 30 countries around the world. Twelve cohorts have been included in this report, representing 59,232 patients, or a total of 249,898 person-years, and capturing 5,444 patients with any

fracture; 3,495 with osteoporotic fractures; and 957 hip fractures. All references were based on peer reviewed publications.

Prof Kanis then gave a live, online demonstration of the FRAX™ tool, offering different examples of a patient's 10-year probability of fracture, based on nationality, patient data including age, gender, height, weight, and risk factors, with or without T-score. This tool will assist primary care physicians determine those patients needing treatment and those requiring reassurance. The program will be updated as new data is received.

When asked about cost effectiveness of intervention, Prof Kanis admitted this was difficult to produce due to a lack of reliable cost effectiveness data which is based on complicated criteria such as a nation's economic status, a patient's and a nation's willingness to pay, or a government's need to control healthcare spending by replacing one disease with another.

The full WHO Scientific Group technical report "Assessment of Osteoporosis at the Primary Health Care Level" was provided to all attendees. The FRAX™-tool is available on line, free of charge, at www.shef.ac.uk/FRAX



The United Kingdom has published a policy document: Falls and Bone Health in Older People: the need for integrated care.

Consultation Panel member Prof David Marsh began his presentation by showing that osteoporotic fractures account for 70% of all inpatient fractures, adding that 1) ~20% excess mortality at 1 yr, 2) 25% never get back to own home, 3) 80% elderly women would rather die

than have a hip fracture, and finally that 4) this tests the entire healthcare system.

He stated that “fractures lead to future fractures, but we can do something about it” The typical patient will have osteoporosis for many years and experience several fractures. The ideal model requires excellent inpatient care, including multiple co-morbidities; reliable secondary prevention for every fracture patient; a chronic disease model that cares for patients between episodes of fracture and responds efficiently to each new fracture; and an understanding of the relationship between osteoporosis drugs and fracture healing.

Models of care that are most effective, in the UK, include fracture liaison nurses in the fracture clinic, and fragility fracture nurse coordinators for inpatients.

Successful models need local agreement on referral mechanisms between fracture service, osteoporosis service and falls service that must involve primary care. Prevention has to be life-long, and it is essential to empower the patient by thorough education. Fracture prevention crosses all patient populations from post-menopausal (PM) women, to PM women with osteoporosis, PM women with prior fracture and those PM women with new fracture each year. Other models must include primary prevention in childhood through to secondary care.

In the UK, the POLICY is that elderly fragility fracture patients should receive secondary prevention – falls and osteoporosis. The REALITY is that no more than 25% of UK elderly incident fragility fracture patients actually receive this. Prof Marsh urged firm top-down guidance to commissioners from the Department of Health, “with achievement that depends on linking our goals to their strategic goals.”

The British Geriatric Society has established a collaboration with the British Orthopedic Association with the shared aim of improving the clinical care of patients with fragility fractures and promoting effective secondary prevention to reduce future falls and fractures. This is achieved by recognising the wide variation between hospitals and regions, postal code inconsistencies, and other chronic conditions.

Prof Marsh concluded by declaring that integrated fracture care, particularly orthogeriatric collaboration, can reduce length of stay, reduce complications, and reduce interference of trauma work on elective orthopaedic work.

Prof Socrates Papapoulos, Consultation Panel Senior Advisor, chaired an open panel discussion with Professors Kanis and Marsh.

He suggested that Panel members 1) submit their ideas on how to effectively use the Audit Report 2) identify ONE key target that will make a difference in osteoporosis healthcare in their country, and 3) identify at least 3-4 names of key policy leaders who they will contact when disseminating the Report.

Other suggestions urged Panel members to prepare a 1-page ‘user friendly’ summary of their country’s care gap and recommendations for improvement, based on the Report, and that IOF prepare a ranking system for data results vs alphabetical listing of country.

In his closing remarks, the IOF CEO, Mr Dan Navid, invited Consultation Panel members to next meet on Monday, October 13, 2008 in Brussels. The meeting is planned to be held as part of the European WOD the following day, where the Audit Report will be launched among other activities. MEPs will be also invited. These WOD activities are expected to attract significant media attention.



To request high resolution photos or additional photos not shown here, please contact Margaret Walker at mwalker@iofbonehealth.org