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Note: Although most member societies are from nations, the IOF membership also includes independent territories, commonwealths, protectorates and geographical areas.

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IOF Scientific Publications

Osteoporosis International (the only international scientific journal devoted entirely to osteoporosis)
Progress in Osteoporosis (summaries and critical analyses of the current literature)

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Please contact Daniel Navid, IOF,
71 cours Albert Thomas, F-69003 Lyon, France,
tel +33 472 91 41 77, fax +33 472 36 90 52,
e-mail: info@osteofound.org



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Dear Readers

If a glass of wine contains 50% it can be seen as either half empty or half full.

In the case of osteoporosis there are those who see a basically empty glass – the way in which administrations, health insurances, physicians and other decision makers deal with osteoporosis, is still a veritable disaster. Then there are those who see a glass which is actually half full – they are delighted that diagnosis and treatment of osteoporosis has been improving steadily and that awareness is increasing all over the world.

Let's assume that the glass is at least half full, and let's say "Cheers" to success in Lisbon, with a good (full) glass of vino verde.

Yours

Helmut Minne

The International Osteoporosis Foundation (IOF) is an independent non-profit umbrella organisation dedicated to the worldwide fight against osteoporosis. IOF's network includes 128 member societies from 69 countries.

IOF's Vision

- A world without osteoporotic fractures

IOF's Mission

- To increase the awareness and understanding of osteoporosis
- To support national osteoporosis societies in order to maximise their effectiveness
- To motivate people to take action to prevent, diagnose and treat osteoporosis

IOF's Goals

- Nurture and enlarge the IOF network of member societies worldwide
- Promote medical innovation and improved care
- Expand IOF partnerships with organisations working on similar or complementary issues and projects
- Lobby for policy change in all countries so that diagnosis and treatment of osteoporosis becomes routine

Scientific research and patient advocacy: working for a common cause

Osteoporosis is recognised as a major health problem which is growing to epidemic proportions all over the world. In response, an osteoporosis "social" movement has evolved which is growing in size and strength. Patient and medical societies have been established in almost all regions of the world, and great strides have been made in increasing education and awareness of osteoporosis among the public, health professionals and health policy makers.

The underpinning of this "social" movement is the work of scientists whose research on bone cell biology, epidemiology, diagnosis and treatment has greatly expanded our knowledge of osteoporosis. The tremendous improvement in diagnostic tools and more effective drugs to prevent bone loss, and reduce fracture occurrence, now mean that osteoporosis can be treated effectively.

In May 2002 the world's leading researchers and osteoporosis specialists will gather in Lisbon to share new knowledge with an audience of over 4,000 physicians, scientists and health care professionals. In conjunction with this scientific event, IOF patient society representatives, partners and sponsors will meet at the IOF World Wide Conference of Osteoporosis Patient Societies to share experience and gain knowledge. Together, these two pillars of the osteoporosis movement - scientific advance and patient advocacy - are working to ensure that the future will be brighter for people with osteoporosis.

What's new in Lisbon?

by Dr. Ego Seeman, member, IOF Board

With hundreds of presentations and posters, how can a visitor make sense of the exciting news that will be presented at the IOF World Congress on Osteoporosis?

Roughly, the new data fall into five categories: Treatment, epidemiology/policy, quality of life, male osteoporosis, and our understanding of the disease's development. Below is a summary, based on an analysis of the abstracts. See the IOF website www.osteofound.org for an annotated version of the text below.

Treatment

The most exciting data concerns a wealth of evidence supporting the efficacy and safety of new therapy for prevention of bone loss, restoration of bone mass, structure and strength using anabolic agents such as intermittent subcutaneous injection of parathyroid hormone (PTH) and oral strontium ranelate. The former increases cortical and trabecular thickness and may increase trabecular connectivity. The latter increases bone formation and reduces bone resorption. The new antiresorptive drug ibandronate reduces spine and nonspine fractures. Residronate maintains trabecular architecture, reduces spine and nonspine fractures within 12 months, and halves intertrochanteric hip fracture risk in over 80 year olds (not just in 70-79 year old women as believed). Alendronate reduces spine frac-



Built in 1960, the Monument of the Discoveries in Lisbon is a modern tribute to Portugal's seafaring explorers and was built on what was the departure point for many voyages of discovery, including those of Vasco da Gama. An appropriate symbol for the voyage of discovery that awaits the participants of the IOF World Congress on Osteoporosis?

ture risk in women with osteopenia as well as osteoporosis, and increases bone density in women and men with primary and secondary osteoporosis. Raloxifene is likely to have benefits outside the skeleton such as reducing the risk of breast cancer and ischemic cardiac events and may protect the skeleton in men as well as women. Newer drugs such as minodronate, a bisphosphonate, and bazedoxifene acetate, a third generation SERM, expand the therapeutic alternatives in the field. The ease, safety and efficacy of new regimens like once weekly alendronate and residronate, three monthly ibandronate, neridronate or pamidronate, and once yearly zoledronate reduce the inconvenience, adverse events and improve compliance. There are many other advances

and confirmatory work regarding antifracture efficacy of vitamin D and calcium, alendronate in women and men with primary and secondary osteoporosis, the combination of monofluorophosphate and raloxifene, and reanalyses of the calcitonin PROOF study.

Epidemiology/policy

Data presented at the congress shows that the importance of vertebral fractures is underestimated, costing €329 million annually with a hospital cost only 25% less than hip fractures while quality of life is reduced more severely than following hip fractures. A portuguese study shows that hip fracture hospital costs (€6000 per patient) are twice that of treating obstructive airways disease or myocardial infarction, three times more costly than alcoholic liver disease. Despite this, the community, governments, and doctors, do not recognise the burden fractures impose of quality, duration and cost health to the community. Despite evidence that drug therapy is cost effective, doctors are not investigating or treating women or men with fractures.

Quality of life

New studies show that hip fractures have profound impact on quality of life. Twenty percent of patients die within the first six months of fracture, fewer patients are able to live at home, and require nursing homes or help from family members or health professionals, and many require assistance in daily activities.

Male osteoporosis

Data confirms that fractures are a serious problem in men as well as women. The mortality following hip fracture is greater in men than in women. The prevalence of spine fractures is similar in men and women, about 15-25%. Estrogen deficiency is important in men as well as women and may be more important than testosterone deficiency as a cause of bone loss while testosterone regulates bone size in males. Smoking interferes with production and increases the degradation of estrogens and produces bone fragility in men as well as women.

How osteoporosis develops

The availability of new treatments is impor-

tant because fractures of any kind predispose to more fractures independent of BMD, bone loss accelerates as we age, and bone fragility increases out of proportion to the amount of bone lost.

Bone fragility in old age has its origins in youth, if not during intrauterine growth. Maternal leptin levels may affect bone mass in the fetus, vitamin D deficiency, protein malnutrition, sex hormone deficiency in growth influence peak skeletal size and density. Many other risk factors amenable to intervention cause bone loss in adulthood and are discussed in 17 different abstracts. New evidence is presented showing measurement of circulating biochemical markers of remodeling predict bone loss, fracture risk and response to drug therapy. The epidemic proportions of fractures parallel the problem of infections, ischemic heart disease, tobacco use and other diseases. The concerted efforts of scientists and governments throughout the world are needed to reduce the health burden of fractures that will drain the health care resources if not recognised.

The Portuguese National Association Against Osteoporosis

In Portugal, like in most European countries, osteoporosis represents a serious public health problem, affecting more than a half-million people, with an estimated 30-35,000 fractures per year.

APOROS – Associação Nacional contra a Osteoporose (National Association against Osteoporosis) was founded in February, 1994 following the national campaign led by the scientific society SPODOM (Portuguese Society of Metabolic Bone Diseases) and is now a well recognised organisation working nationally to fight osteoporosis.

As a patient-oriented and non-profit society APOROS' main objectives are to provide the general public with the correct information on osteoporosis, to promote medical assistance and research on the disease, to encourage its prevention and early diagnosis, and to assist sufferers and their families.

During the eight years since its launch, many activities have been undertaken to attain these objectives. These range from the publication of informational leaflets and meetings with patients and the general public, to press conferences, radio and television advertisements and programs. Awareness activities, although taking place all-year round, are focused mainly around World Osteoporosis Day (WOD). The WOD events usually last

from one to two weeks and primarily stress the importance of exercise and healthy lifestyles.



World Osteoporosis Day 2001 event

In Portugal access to diagnosis is unrestricted and bone mass measurements are reimbursed. However, most DXA machines are in private centres located in major cities, and although being a small country, access to those centres may be a problem for people (especially older people) living in small villages. One of APOROS main projects, now on its second year, is a screening program for post-menopausal women and older men, which gives the inhabitants of these small villages the possibility to screen for the disease at no cost. In this program APOROS

uses four peripheral DXA units (with the financial support of a pharmaceutical company) that are installed for a couple of days in each local public health centre. To date more than 25 000 men and women have been screened in this cooperation project and results confirm an osteoporosis prevalence of 18-20% in the evaluated population, similar to the rates previously found in epidemiological studies.

“Most DXA machines are in private centres located in major cities ...access to those centres may be a problem for people (especially older people) living in small villages.”

With the recent opening of the new office, offered rent free by the municipality of Lisbon, APOROS hopes to expand its activities. A great challenge will be the IOF World Wide Conference of Osteoporosis Patient Societies that will take place in May, 2002 and which APOROS is organising together with IOF. APOROS looks forward to welcoming its fellow IOF member society representatives to Lisbon.

Contributed by Viviana Tavares, President, APOROS



Contributed by
Michael McClung

Dr. McClung is founding director of the Oregon Osteoporosis Center and an internationally recognised expert in the fields of osteoporosis and bone density testing. He is a member of the IOF Committee of Scientific Advisors and serves on the Scientific Advisory Board of the National Osteoporosis Foundation (US).

Management of osteoporosis in the USA

The management of osteoporosis in the United States is influenced by a complex interplay of government policy and mandates, private insurance and health systems, interest and awareness among physicians and the assumption of personal responsibility for health care decisions by patients. The awareness of osteoporosis by all concerned has increased substantially in the past few years. The impetus for this increase in both awareness and interest is the availability of therapeutic agents that clearly reduce the risk of fractures and of better strategies for identifying patients with, or at risk of, osteoporosis.

This increase in the visibility of osteoporosis as an important health concern has been driven by a strong advocacy for the disease by our National Osteoporosis Foundation (NOF). This organization has effectively influenced government to increase spending for osteoporosis research and has promoted initiatives in many states, establishing state-funded educational initiatives about osteoporosis. Many of these efforts have targeted reimbursement for bone density testing. Awareness has also been increased by other professional societies interested in skeletal disorders and women's health and, importantly, by both the educational and marketing activities of the pharmaceutical industry. The latter includes direct-to-consumer awareness campaigns and direct advertising

for the major drugs for treating osteoporosis. The efforts of the pharmaceutical companies and of most societies have been aimed at younger postmenopausal women and even premenopausal women and children. As a result, the awareness of osteoporosis among young postmenopausal and premenopausal women is quite high. They now ask for and even expect to have a bone density test performed as a part of the regular medical evaluation. Unfortunately, older women are less aware that osteoporosis is common at their age and that treatment is available. More attention needs to be focused on improving awareness among older women and in men.

Access to bone density testing is now very good in this country. More than 12,000 bone density testing devices – mostly central DXA units – are now in place. Recent estimates are that as many as half of postmenopausal women have had a bone density test performed. This is the result of efforts of both the NOF and the pharmaceutical companies. Guidelines provided by the NOF in 1998 suggested that BMD testing was appropriate for all women over age 65 and for younger postmenopausal women and men with important risk factors for fracture. These guidelines were the basis of the Bone Mass Measurement Act of 1999, legislation passed by our federal Congress providing reimbursement for BMD testing for estrogen-deficient women of Medicare age (65 and older) and others with risk factors for osteoporosis or fracture. Most private insurance companies reimburse BMD testing in their Medicare population based on this legislation. Reimbursement for testing of younger women and men without risk factors for fracture is much more variable. Other societies including the American Association of Clinical Endocrinology and the North American Menopause Society have reinforced recommendations for BMD testing with their own guidelines.

Access to prescription medication to treat osteoporosis depends almost solely upon on the specific health care coverage of individual patients. Coverage for medications is not provided by Medicare, and most health insurance companies do not provide prescription benefits to their older Medicare-eligible patients. In contrast, most younger patients do have medication coverage as a part of their health insurance. As a result, many younger, low risk patients have easy access to medications to treat osteoporosis while older patients – those at higher risk for whom the medications are most valuable – are usually required to pay for the drugs by themselves. Being personally responsible for the cost of the drugs is probably a significant factor in the low treatment rates

among older patients known to have osteoporosis. Whether a patient chooses to pay for the drugs is also influenced by the clarity and enthusiasm with which their personal physician conveys the necessity and the benefits of treatment. Unfortunately, the importance of treatment is often not made clear to the patient by the physician. There is still a strong perception among physicians that little can be done to treat osteoporosis.

“More attention needs to be focused on improving awareness among older women and in men.”

The interplay among government, industry, the health care professions and national societies in the United States to develop initiatives for the identification and treatment of patients with osteoporosis and to reduce the incidence of fractures is still evolving. We have been successful in increasing public awareness among relatively young women at low risk for osteoporosis and fractures, and there is much discussion about how osteoporosis might be prevented. In contrast, the awareness among older adults who are more likely to have osteoporosis and to benefit from treatment is relatively low, and many physicians are just realizing that treatment is most appropriate in those patients at highest risk for fracture. This important disparity between where the awareness is and where the high risk patients are needs to be addressed if the efforts of the medical community and the advocates of osteoporosis awareness are to have an important impact on the disease.

Our approaches to osteoporosis management and their effectiveness will continue to improve as more solid evidence accrues from research studies about the clinically appropriate and cost-effective use of our diagnostic and treatment options.

“Whether a patient receives treatment is influenced significantly by their ability to pay for the medications.”

The OSC's "No Fracture is Acceptable" Campaign

In Canada, healthcare is the responsibility of the provincial governments. In 2001 the Osteoporosis Society of Canada (OSC) won an IOF-Lilly Policy Initiative Grant for its "No Fracture is Acceptable" campaign which was carried out in four provinces. The aim of the campaign was to increase the range of drug therapies available, to reduce restrictive criteria applied to accessing newer therapies and to increase the number of DXAs in underserved areas.

The campaign in each province had a three-pronged approach: political, grassroots, and communications/public relations. Each campaign was planned locally in consultation with the National Office. Each strategy was modified and modifications adapted to suit each province.



The outcomes of the "No Fracture is Acceptable" campaign were heightened awareness of elected politicians and public service employees; a core group of media trained

One of the OSC's many dedicated volunteers, she herself has osteoporosis, staffs a call in telephone line.

osteoporosis spokespersons in each province; the development of advocacy tools that can be used to influence national policy; volunteers learning to work together to have their voices heard; expansion of the listed drug therapies, and increased access to DXA. Another key result was the development of a network of trained volunteer advocates that can be called upon for other advocacy issues that may arise.

Contributed by Joyce Gordon, Osteoporosis Society of Canada, President and CEO

In Nova Scotia, one of Canada's 10 provinces, thousands of people joined an extensive OSC letter-writing campaign calling for the government to increase the number of bone density machines in their province. Nova Scotia now has only three bone densitometers to serve the needs of almost one million residents. This means that people have to travel up to four hours for testing and waiting lists range from three to 12 months. This also delays treatment, because patients do not have access to newly approved treatments until they have had a bone density test.



Jean Murdock, left, and Dr. Diane Theriault, of the OSC Nova Scotia Chapter, with thousands of letters from citizens advocating for improved access to BMD testing in their province.

Queen Rania of Jordan helps launch Mexican bone education programme

In March 2002 Her Majesty Queen Rania of Jordan, IOF Patron, visited a primary school in Mexico City at the invitation of the Comité Mexicana para la Prevencion de la Osteoporosis A.C. (COMOP). Her visit was a major event which helped to draw attention to, and support for, COMOP's pilot primary school bone education programme.

The multi-faceted COMOP programme focuses on teaching parents, educators and children about bone health and osteoporosis prevention and diagnosis. COMOP doctors hold seminars with teachers and parents and help teachers develop educational material to use with the children. Parents are also involved in that they are encouraged to prepare and give seminars with counseling from COMOP about themes related to bone health like nutrition and exercise. With the help of education material, the children are given instruction in bone health and are asked to take a risk factor questionnaire home to be

completed by their family members – parents, siblings, grandparents, aunts and uncles. Playing the "reporter's" role the child helps to extend awareness of osteoporosis outside the classroom. In addition, densitometry testing is performed on family members

who have completed the risk questionnaire in order to determine the genetic risk of osteoporosis in each family and as part of a study whose results will be used to develop a database of peak bone mass accrual by Mexican children.



A great honour for the children and guests, Queen Rania of Jordan's visit to the "Escuela Maestro Manuel Acosta" was the highlight of the successful launch of COMOP's bone education programme. Her Majesty's visit boosted plans to launch the programme in other Mexican City schools, and with time, to other cities in the country.

Front row from left: Actress Angélica María, COMOP goodwill ambassador, Queen Rania with pupils, and Mr. Carlo Esponda representing the Mexican Health Ministry

China's Vice-Minister of Public Health meets with COF and IOF officials



The First International Conference on Bone and Mineral Research (ICBMR), organised by the China Osteoporosis Foundation (COF), was held in September 2001. China's Vice-Minister of Public Health, Mr. Zhu Qingsheng, showed the government's support for the conference by meeting personally with IOF's president and officials of COF.

The First International Conference on Bone and Mineral Research (ICBMR) was held from September 15 to 19 at the Beijing International Hotel. The conference, sponsored

by the China Osteoporosis Foundation (COF), attracted about 550 health professionals from China and abroad. IOF President Professor P. D. Delmas,

addressed the meeting on IOF work in the past three years. His report was warmly received by the attendees. COF and the Osteoporosis Committee of China's Gerontological Society (OCCGS) are active members of IOF's family of 128 member societies and play a prominent role within the Asian osteoporosis movement.

A sign of the high level of government interest for the conference was the personal support shown by Mr. Zhu Qingsheng, vice-minister of public health. At a special reception Mr. Zhu met with Professor Delmas and other international specialists, Professor Liu Zhonghou, president of COF, and Professor Zhang Liping, honorary president of COF. The Vice-Minister expressed his appreciation for the support and help IOF has offered to COF and OCCGS.

Captain Mike's campaign: The school milk package with the osteo message

For over a year now, thousands of children all over Lebanon have been receiving a small carton of milk every morning: courtesy of Captain Mike. Captain Mike, for those who don't know, is a swashbuckling young pirate, who drinks milk to grow strong, as all children should!

Captain Mike does not just deliver milk. He comes as a complete package that includes a school education program comprising advice for parents and children on lifestyle issues such as environmental awareness and nutritional health. It is in this context that LOPS has been invited to collaborate in the project.

With this in mind, an animated projector presentation was designed by LOPS, aimed at explaining to parents about osteoporosis and focusing in particular on child nutrition. During the presentation, parents are advised of the vital importance of investing in their children's bones: that children have a once-in-a-lifetime opportunity to achieve peak bone density during their adolescent years. Much of the presentation was drawn from IOF's 'Invest in Your Bones' report, authored by Prof. Jean-Philippe Bonjour. Various members of LOPS' committee give presentations at schools around the country in Arabic or English, as required.

The Captain Mike programme aims to provide milk to as many schools as possible. Parents of children at more affluent schools pay approximately US\$ 20 per year for their

child's milk, and for every three such children, one needy child will receive milk free.

Many private donors and charities (e.g. the Rotary Club) are contributing to this initiative, as are also the local dairy farms involved in the program. Some schools are also sponsoring other schools or institutions in need. This innovative scheme is the brain-

child of Ms. Kelly Boucher of Tetrapak, original sponsors of the program. Ms. Dania Rifai, of the Lebanese Development Association is responsible for its implementation in Lebanon.

Captain Mike is a busy little pirate. Not only is he zipping around Lebanon, but he has also been spotted in Jordan, and is promising to visit other Arab countries in the near future. We wish him well with an initiative that can only spell good news for all concerned.



Twinning project hosted by the OSC

In February 2002, the Israeli Foundation for Osteoporosis and Bone Diseases (IFOB) participated in an IOF sponsored twinning project with the Osteoporosis Society of Canada (OSC). Irit Inbar, IFOB's executive manager, brought home valuable knowledge gained during her participation at the OSC's volunteer training and development workshop. Stating that "I have already adapted some of this knowledge for IFOB programmes", Mrs. Inbar, who praised the workshop and OSC's hospitality, was also able to profit from additional educational activities which focused on fundraising, establishing support groups and information lines.

IOF encourages and provides financial support for twinning projects that help newly established, smaller societies benefit from the experience of larger and well-established societies such as the OSC.



Participants of the Osteoporosis Society of Canada's volunteer training and development workshop

Thai Osteoporosis Foundation launched in Bangkok

The First Asian Regional IOF Conference on Osteoporosis was held in Bangkok from February 27 to March 1, 2002. The commitment and enthusiasm of the organising committee (physicians working in fields related to the prevention, diagnosis and treatment of osteoporosis) and the Committee's Chairman, Dr. Suthorn Bavonratavech contributed to the success of the conference. International guest speakers included IOF President Pierre D. Delmas; IOF General Secretary Jean-Yves Reginster; IOF CEO Daniel Navid, as well as board members John Kanis, Rene Rizzoli and Ego Seeman. About 600 physicians from 22 countries attended, with half of this number coming from Thailand.

The ultimate goal was to have participants come away with valuable knowledge and understanding of osteoporosis, while establishing a network of professionals with common aims. As an important step in raising national and regional awareness of the immediacy and seriousness of osteoporosis, the conference was also the ideal venue to launch the newly formed Thai Osteoporosis Foundation. The mission of the Thai Osteoporosis

Foundation is to help improve the bone health of people in Thailand as well as to reduce the incidence of bone fractures which lead to disability, loss of life and mounting medical expenses. The Thai Osteoporosis Foundation was honoured to have Her Royal Highness Princess Galyani Vadhana KromLuang Naradhiwas Rajanagarindra place the Foundation under Her Royal patronage. Her Royal Highness also graciously accepted to be the Foundation's Honorary Chairperson.



The conference was inaugurated by Her Royal Highness Princess Galyani Vadhana Krom Luang Naradhiwas Rajanagarindra. Above: IOF President Pierre D. Delmas explains to Her Royal Highness the results of her ultrasound test – fortunately all is well!



PATIENT STORY

Anna Meys, Belgium

94-year old Anna Meys is one of the 23 courageous people with osteoporosis who volunteered to be photographed by the renowned photographer Olivier Toscani for the exhibit "Osteoporosis: A Photographic Vision". Anyone who views Anna's portrait sees the face of a lovely elderly lady – the beautiful smile does not reveal the pain and suffering she has endured as a result of osteoporosis and rheumatoid arthritis. In contrast, the full-length photos shown at the exhibit, without the ordinary camouflage of clothing, reveal the severe effects of osteoporosis on Anna's body. Anna's osteoporosis has resulted in several broken bones – including fractured ribs and an elbow. Spinal compression fractures have caused her to lose 10 cm in height, so that she is now only 1.49 m. tall.



Anna considers herself fortunate to have been fairly independent until her 90th year when she became wheelchair bound. She did not suffer a debilitating hip fracture as do many elderly osteoporosis patients.

Perhaps this is because Anna has had the best possible care. Her daughter, Dr. Christine Pouliart, is a member of IOF's scientific advisory committee and founder of the Belgian Association for Osteoporotic Patients. Anna was given anti-resorptive treatment beginning

in her late 60's and has always received appropriate medication to manage her pain. Most osteoporosis sufferers of Anna's generation are not as fortunate. Osteoporosis was not officially recognised as a disease by the World Health Organization until 1994 – when Anna was already in her 80's.

Younger generations can now benefit from improved awareness and knowledge about osteoporosis, not to mention more diagnosis and treatment options. There is no longer any excuse for the lack of early prevention, diagnosis and treatment that is sadly still so common everywhere.

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