



On behalf of the Board of the International Osteoporosis Foundation, we would like to extend a warm and personal welcome to all the members of the former EFFO and IFSSD who are now part of the new organisation. As an umbrella organisation, IOF exists for its members. Our door is therefore always open, and we will be delighted to receive your comments, suggestions and constructive criticisms about the work of IOF. We are looking forward to working with all our members to reduce the global impact of osteoporosis in the years to come.



Prof Pierre D Delmas,
President



Mary Fraser,
Executive Director

IOF Board:

Prof. Maurice Audran; Prof. Peter Burckhardt; Dr Claus Christiansen; Prof. Pierre D Delmas (President); Prof. Jean Pierre Devogelaer; Mrs Linda Edwards; Prof. Herbert Fleisch; Prof. Carlo Gennari; Prof. John A Kanis; Prof. Uri Liberman; Prof. George P Lyritis; Prof. Pierre J Meunier; Prof. Helmut Minne; Prof. Socrates Papapoulos; Prof. Jean-Yves Reginster; Prof. Johann Ringe; Dr René Rizzoli (ex officio); Mr Leo van Wersch (ex officio).

IOF Committee of Scientific Advisors:

Prof. Silvano Adami, **Italy**; Prof. Erik Allander, **Sweden**; Prof. Jean-Philippe Bonjour, **Switzerland**; Dr Aurelio Borelli, **Brazil**; Prof. Maria Luisa Brandi, **Italy**; Dr Narong Bunyaratavej, **Thailand**; Prof. Peter Burckhardt, **Switzerland**; Dr Daniel Chappard, **France**; Prof. Claus Christiansen, **Denmark**; Dr Juliet Compston, **UK**; Prof. Cyrus Cooper, **UK**; Prof. Marie-Christine de Vernejoul, **France**; Prof. Pierre D Delmas, **France**; Prof. Jean Pierre Devogelaer, **Belgium**; Prof. Martina Dören, **UK**; Dr Erik Fink Eriksen, **Denmark**; Prof. Dieter Felsenberg, **Germany**; Prof. Herbert Fleisch, **Switzerland**; Prof. Carlo Gennari, **Italy**; Prof. Piet Geusens, **Belgium**; Prof. Claus Glüer, **Germany**; Dr Shi-fu Guo, **China**; Prof. Olof Johnell, **Sweden**; Prof. John A Kanis, **UK**; Dr Jean Marc Kaufman, **Belgium**; Prof. Uri Liberman, **Israel**; Dr Paul Lips, **The Netherlands**; Dr Sverker Ljunghall, **Sweden**; Prof. Roman Lorenc, **Poland**; Dr Frank Luyten, **Belgium**; Dr Daniel Messina, **Argentina**; Prof. Pierre J Meunier, **France**; Dr Sergio Orlotani, **Italy**; Prof Socrates Papapoulos, **The Netherlands**; Prof. Mario Passeri, **Italy**; Dr Gyula Poor, **Hungary**; Dr Christine Pouliart, **Belgium**; Dr Jonathan Reeve, **UK**; Prof. Jean-Yves Reginster, **Belgium**; Prof. Johann Ringe, **Germany**; Dr René Rizzoli, **Switzerland** (Chairman); Dr Christian Roux, **France**; Dr Graham Russell, **UK**; Prof. Markus J Seibel, **Germany**; Prof. Alan Silman, **UK**; Dr Jan Stepan, **Czech Republic**; Dr Christian Wuster, **Germany**.

IOF Committee of National Societies:

Argentina: Sociedad Argentina de Osteoporosis; **Austria:** Austrian Menopause Society, Austrian Society of Bone and Mineral Research, Österreichische Osteoporose Selbsthilfe*; **Belgium:** Belgian Bone Club, Société Royale Belge de Rhumatologie; **Brazil:** Brazilian Society of Osteoporosis; **Chile:** Chilean Society of Osteoporosis and Mineral Metabolism; **China:** Osteoporosis Committee of China Gerontological Society; **Cuba:** Sociedad Cuba de Reumatología; **Czech Republic:** Czech Society for Metabolic Skeletal Diseases; **Denmark:** Danish Bone Society, Osteoporoseforeningen*; **Estonia:** Estonian Orthopaedic Society; **Finland:** Finnish Osteoporosis Society, Finnish Bone Society; **France:** Association des Femmes contre l'Ostéoporose*, GRIO; **Germany:** Bundesselbsthilfeverband für Osteoporose, Deutsche Gesellschaft für Osteologie, German Academy of the Osteological and Rheumatological Sciences, German Society for Endocrinology, Kuratorium Knochengesundheit; **Greece:** Hellenic Society for the Study of Bone Metabolism; **Hungary:** Hungarian Society for Osteoporosis; **Iceland:** Beinvernd*; **India:** Indian Rheumatism Association; **Ireland:** Irish Osteoporosis Society*; **Israel:** Israel Society on Calcified Tissues; **Italy:** Italian Society for Mineral Metabolism, Italian Society for Osteoporosis, Italian

ANNOUNCEMENTS FROM THE CONGRESS

New date for World Osteoporosis Day

From 1999 onwards, World Osteoporosis Day will have a new date – October 20. The theme for World Osteoporosis Day 1999 is EARLY DETECTION.

New logo for World Osteoporosis Day

IOF is working with the Lega Italiana Osteoporosi to create a new logo in honour of World Osteoporosis Day's new date.

IOF at EXPO 2000

IOF plans to be present at EXPO 2000 in Hannover between June and October 2000. As part of the "Health Futures" area, IOF will be aiming to inform as wide a public as possible about osteoporosis and the new advances in research that make it a preventable and treatable disease rather than an inevitability. IOF will highlight the need for early detection of osteoporosis, and demonstrate the latest technology used to spot the disease.

Society of Rheumatology, Lega Italiana Osteoporosi; **Japan:** Japanese Society for Bone and Mineral Research; **Lebanon:** Lebanese Osteoporosis Prevention Society; Société Libanaise de Rhumatologie; **Lithuania:** Institute of Endocrinology, Lithuanian Fund of Osteoporosis*; **Luxembourg:** ALEMO; **Norway:** Norsk Osteoporoseforening, Norwegian Society for Rheumatology; **Philippines:** Osteoporosis Society of the Philippines; **Poland:** Multidisciplinary Osteoporotic Forum, Polish Foundation of Osteoporosis; **Portugal:** APOROS, Ass. Portuguesa de Osteoporose (APO), SPO-DOM; **Romania:** Romanian Society of Osteoporosis, Romanian Society of Rheumatology; **Russia:** Russian Association on Osteoporosis; **Saudi Arabia:** Saudi Osteoporosis Club*; **Slovak Republic:** Slovak Society of Osteoporosis and Metabolic Disease; **Slovenia:** Slovene Bone Society; **South Africa:** National Osteoporosis Foundation**; **Spain:** FHOEMO, SEIOMM; **Sweden:** ROP, Swedish Osteoporosis Society; **Switzerland:** Association Suisse Contre l'Ostéoporose, Donna Mobile*; **Thailand:** Thai Orthopaedic Association; **The Netherlands:** Dutch Society for Calcium and Bone Metabolism, Osteoporosis Stichting, Osteoporose Vereniging; **Turkey:** Rheumatism Society; **UK:** Bone and Tooth Society, National Osteoporosis Society; **Ukraine:** Ukraine Association on Osteoporosis; **USA:** International Society for Clinical Densitometry.

*Associate member, **Corresponding member

OF Committee of Corporate Advisors:

Abiogen Pharma srl, Asta Medica, Beckman-Coulter, Besins Iscovesco, Byk Gulden Lomborg Chemische Fabrik GmbH, Cassenne, Chiesi, Cilag International, Eli Lilly Italia SpA, Hoeschst Marion Roussel Inc, Hoffmann-La Roche Ltd, Hologic Europe NV, IGEA srl, IRIS, Johnson & Johnson Clinical Diagnostics Ltd, Lunar Europe NV, Merck KGaA, Metra Biosystems, MSD, Nestlé Suisse SA, Norland Medical Systems Inc, Novartis, Novo Nordisk A/S, NV Organon, Osteometer Biotech, Osteometer MediTech A/S, Ostex Europe Ltd, Pfizer, Pierre Fabre Médicaments, Procter & Gamble Pharmaceuticals Europe, Rhone Poulenc Rorer, Rotta Research Laboratorium, Schering AG, SmithKline Beecham, Strathmann AG, Sunlight Ultrasound Technologies, Teva Pharmaceutical Industries Ltd, Theramex, Union Chimique Belge (UCB), Wyeth Lederle, Yamamouchi Europe BV.

IOF Staff:

Executive Director: Mary Fraser; **Office Manager:** Véronique Forterre; **Funding Advisor:** Margaret Reilly Baer; **Assistants:** Véronique Chabanis, Silvy Grazioli, Claude Raynal.

Contact details for National Societies can be obtained from IOF website <http://www.osteofound.org> or via the IOF Secretariat in Lyon, tel +33 472 914177, fax +33 472 369052, e-mail: osteofound@net.asi.fr.

Editors-in-Chief Osteoporosis International: R Lindsay (USA), PJ Meunier (France)
Editor IOF News: H Minne (Germany)

Acknowledgements

Many thanks to all those who contributed to IOF News. IOF News is supported by Osteoporosis International, the scientific journal of IOF and American NOF, published by Springer-Verlag London Ltd (tel +44 1 483 41 41 42, fax +44 1 483 42 12 70, e-mail: chris@svl.co.uk)

Feedback & subscription

Please contact Mary Fraser, IOF Secretariat, 71 Cours Albert Thomas, F-69003 Lyon, France, tel +33 472 914177, fax +33 472 369052, e-mail: osteofound@net.asi.fr, IOF website <http://www.osteofound.org>

Letter from the Editor

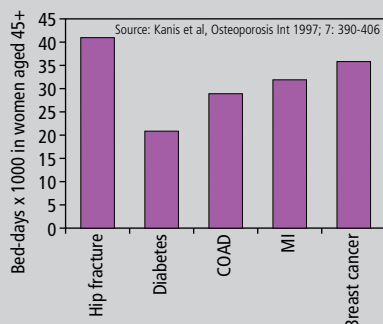


Dear Readers,

A highlight of the Consensus Conference on Clinical Guidelines for Diagnosis and Treatment of Osteoporosis was the agreement between the IOF and the National Osteoporosis Foundation of America that measurement of bone density should be used in all post-menopausal women who have one or more clinical risk factors for fracture, since low bone mineral density leads to fracture as reliably as high blood pressure leads to stroke. As the figure below shows, more hospital beds are occupied by women over 45 with hip fractures due to osteoporosis than by heart attack patients. Is it not scandalous then that some countries are withdrawing reimbursement for BMD measurement, even for people in high risk groups?

Yours sincerely,

Professor Helmut Minne



Hospital bed occupancy in women aged 45 years or more. COAD, chronic obstructive airways disease; MI, myocardial infarction

IOF Mission

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

LAUNCH OF IOF

The European Congress on Osteoporosis in Berlin, attended by about 4000 health care professionals and researchers, was the fitting setting for the launch on 12 September of a major new organisation. The International Osteoporosis Foundation (IOF) has been created from the joint forces of the European Foundation For Osteoporosis (EFO), founded in 1987, and the International Federation of Societies on Skeletal Diseases (IFSSD), founded in 1995.

Professor Pierre D Delmas (formerly President of EFO) and Mary Fraser (formerly Executive Director of EFO) will assume the same positions in IOF. The former President of the IFSSD, Professor Carlo Gennari, will assume the honorary position of Past President.

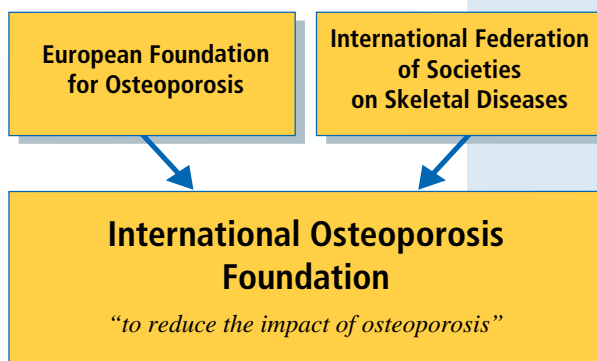
Dr André Prost, Director for Non-communicable Diseases at the World Health Organization, said, "The timing could not be better for the formation of IOF. We have enjoyed a long relationship of collaboration with EFO and IFSSD, and those joint efforts will become, I hope, even stronger now they are a larger organisation with a broader audience and constituency."

The new IOF covers 70 societies from 42 countries and represents the world's largest osteoporosis network. Its members include national osteoporosis societies which are run by medical professionals and health care experts who work closely with patients, government health officials, representatives of the private sector and the media. Speaking on behalf of the national societies Elizabeth de Boer, Director of the Dutch Osteoporosis Foundation, said "EFO was a valuable resource ... with

the Foundation's larger influence as IOF, we will have access to an even stronger support structure."

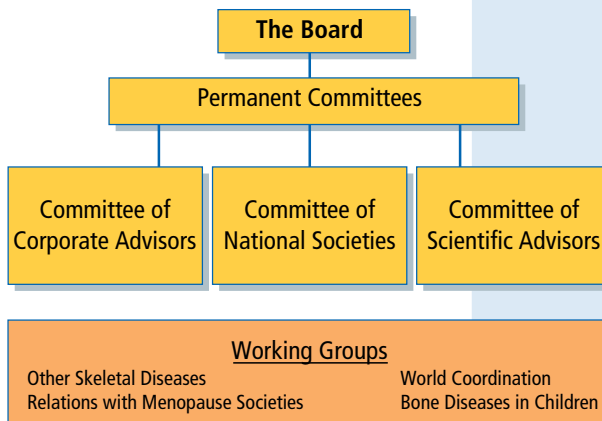
IOF will continue to implement activities on regional and national levels through its members, and maintain its close collaboration with the National Osteoporosis Foundation (America) on common projects such as the Consensus Conference (see centre pages), the scientific journal Osteoporosis International, and the World Congresses. However, the new foundation will now be able to play an international role.

"With the creation of IOF the fight against osteoporosis has become more powerful," said Professor Delmas. "Our new partnership will help to mobilize resources and raise awareness about the 'silent epidemic'".



International Osteoporosis Foundation

"to reduce the impact of osteoporosis"





Opening of the European Congress on Osteoporosis

Berlin, the city that is the new heart of Germany, was host to delegates from around the world at the 1998 European Congress on Osteoporosis. The Congress provided the opportunity for all those concerned about osteoporosis, from scientists to representatives of osteoporosis societies to osteoporosis sufferers, to meet under one roof. The Congress also saw the launch of the new organisation, the International Osteoporosis Foundation. As the old EFO became part of IOF, its role was praised by the wife of the German Bundespräsident, Christiane Herzog, who said "I commend you for your important work for women suffering from osteoporosis."

SCIENTIFIC CONGRESS



Dr André Prost, WHO

The scientific congress, from 12–15 September, was the heart of the European Congress on Osteoporosis. At the opening session Dr André Prost, Director for Non-communicable Diseases, WHO, reminded participants that osteoporosis was only formally recognized as a disease by WHO experts as late as 1994. Since then an impressive amount of progress has been achieved both in recognizing osteoporosis as a public health priority, and in understanding its basic and medical science.

Accumulating evidence underlines that osteoporosis is not a natural consequence of ageing but a disease. Dr Haakon E Meyer of Norway showed that hip fracture patients have a 70% increase in the risk of dying compared to other patients, and Jane A Cauley from the University

of Pittsburgh reported that excess mortality is also linked to other types of osteoporotic fracture. "Fractures are associated with a significant increase in mortality that is not explained by age."

Diagnosis, evaluation and prognosis

Reports from the Congress demonstrate that rapid progress is being made in diagnosis, treatment evaluation and prognosis. Major advances include the use of biochemical bone markers and ultrasound techniques to evaluate the impact of novel therapies on the progress of the disease. Dr Perville Ravn of Denmark presented data from a clinical trial involving over 1000 women, showing that several biochemical markers of bone metabolism, such as osteocalcin, can be used as fast and accurate indicators of the response to treatment. Members of the WHO Collaborating Centre for Metabolic Bone Diseases at the University of Sheffield also presented evidence that broadband ultrasound attenuation is sensitive enough to assess bone changes induced by therapy, and may be used to measure results in clinical trials. Biochemical markers of bone turnover may also be useful as indicators of risk in postmenopausal women: the faster the turnover, reported Dr Patrick Garnero from Lyon, the faster the rate of bone loss.

New therapies

Exciting new therapeutic interventions were on the agenda. Among them is raloxifene, a specific estrogen receptor modulator currently being launched in countries around the world. Dr B Ettinger reported that 24 months of treatment with raloxifene can reduce vertebral fractures in women with osteoporosis by about one half. Furthermore, in a study by Dr Nina Bjarnasson raloxifene decreased bone turnover, increased bone mass and lowered blood cholesterol, all without harmful stimulation of the uterus lining.

Positive effects on bone mass and reduction in fracture rate are also reported from studies using the nasal spray salmon calcitonin, or the bisphosphonate agent alendronate alone or in combination with conventional hormone replacement therapy (HRT).

These advances convey a very positive message: not only are more effective and better tolerated treatments being developed, but more

osteoporosis sufferers are now likely to receive treatment that is optimally tailored to their specific needs.

Quality of life

Even among professionals, awareness of the catastrophic effect of osteoporosis on a sufferer's quality of life can be low. Two questionnaires, one developed by Dr Allison R Martin from Lyon, and the other by the former EFO and presented by Dr Anna Oleksik, have been used to assess quality of life in a total of 1476 women. The results from both questionnaires demonstrate that quality of life deteriorates markedly as osteoporosis develops and vertebral fractures occur. These results provide vital support towards the acknowledgement of the social and economic importance of this disease.

Osteoporosis in men

All too often, osteoporosis in men is underestimated or discounted. Because of this many male sufferers face irreparable delays in having their osteoporosis diagnosed and treated. Results presented by Dr Pawel Szulc, showing that significant bone loss at the hip, forearm and total body can be documented in the majority of men over 50, and that bone loss at the hip can start as early as age 25, were therefore of vital significance.

CONSENSUS CONFERENCE

The Consensus Conference on Clinical Guidelines for Diagnosis and Treatment of Osteoporosis undertook the vital task of establishing consensus for a condition which was only formally recognized as a disease in 1994, and which increasingly is being managed by primary care physicians rather than specialists. Among the agreements were:

Who should have a bone mineral density (BMD) measurement?

Any woman over 65 years of age who is willing to be treated should be eligible for a paid measurement. Below 65 years BMD measurement should be performed in those with risk factors for osteoporosis, which include:

- a maternal history of hip fracture
- personal history of fracture after the age of 45 (including simple loss of height)
- premature menopause and/or prolonged absence of menstruation
- thin build
- use of steroids for longer than 6 months
- smoking
- conditions such as malabsorption from the intestine, hyperthyroidism, prolonged immobilization.

Attendees of the European Congress on Osteoporosis relax at the Roaring Twenties Party:



Dr and Mrs Juan Tamayo (Mexico)



Dr and Mrs H Morii (Japan)



Dr and Mrs C Glüer (Germany)



Former President of IFSSD Prof Carlo Gennari (left) and President of IOF Prof Pierre D Delmas

Which treatments should be used for postmenopausal women?

Evidence-based medicine should be applied to osteoporosis. There are several treatments that have unequivocally demonstrated their ability to decrease the incidence of new fragility fractures, and these should be considered first for the prevention and treatment of osteoporosis. The efficacy of various treatments was briefly reviewed and diagnostic and treatment guidelines will be published early next year in the scientific journal *Osteoporosis International*, together with the proceedings of the congress.

OSTEOPOROSIS PATIENT SOCIETIES CONFERENCE

The launch of IOF was also announced at the 4th Worldwide Conference of Osteoporosis Patient Societies. Assembling over 150 participants from almost 40 countries, this was the first time the Conference has been held in parallel with a major international scientific meeting. The objectives were to bring together the ideas and experience of the different audiences, and to ensure that the osteoporosis patient's voice was heard loudly and clearly in Berlin.

Two visitors to the Conference were Dr André Prost, Director of Non-communicable Diseases, WHO, and Ursula Schleicher, Vice-President of the European Parliament, who gave it their warmest support. Dr Prost listened with keen interest to the national follow-ups to the Report on Osteoporosis in the European Community – Action for Prevention (see *EFFO News* No.3, Vol.2, Summer 1998), which is strongly supported by WHO.

The Conference also saw the award of the first IOF Education Grant. Amounting to US\$ 45000, it will be split between two important projects. The Hungarian Osteoporosis Patient Association intends to use its award to fund training for volunteer managers of osteoporosis self-help groups, while the Lega Italiana Osteoporosi will launch a campaign to raise awareness among pregnant women of the need for an adequate calcium intake to ensure both they and their children have healthy bones.

Events at the Conference demonstrated that the osteoporosis patient movement is growing and becoming active in more spheres, and better organised. In a move to foster links between societies who share the common goal of fighting osteoporosis, the first Directory of Osteoporosis Patient Societies was launched. The Directory was initially requested by participants at the 1997 Patient Societies Conference in Oslo and has been kindly provided by Merck Sharp and Dohme. Attendees at Berlin were also offered the opportunity to participate in professional skills workshops addressing issues of interest to patient societies, including

fundraising, campaigning, communications and patient services.

The next Worldwide Conference of Osteoporosis Patient Societies will be held on 5 and 6 October, 1999 in Toronto, Canada, where the hosts will be the Osteoporosis Society of Canada and IOF.



The Lebanese group celebrates at the Conference dinner

“The Worldwide Conference of Osteoporosis Patient Societies has shown me the human face of osteoporosis. It has forced me to think not just in terms of hard scientific data but of people as well ... It has strengthened our resolve to establish a patient society in India.”

R Handa, MD
Associate Professor of Medicine,
All India Institute of Medical Sciences

Ursula Schleicher, Vice-President of the European Parliament



IOF Education Award winners Dr Istvan Marton (Hungary), Dr Maria Luisa Bianchi (Italy), Dr Ada Bossanyi (Hungary)



PUBLIC EDUCATION DAY

“I am very pleased that this event is being held in conjunction with a major international scientific and patient societies conference.” With these words Prof. Dr Rita Süßmuth, President of the German Bundestag, welcomed almost 1000 visitors to a Public Education Day on 12 September. The Day, an appealing mixture of education and entertainment, was organized in association with IOF by the German Green Cross (DGK) and the Federation of Osteoporosis Self-Help Groups (BfO), the umbrella organization for 230 German self-help groups. The event was hosted by the well-known German TV doctor Günther Gerhardt, and Dr André Prost represented the World Health Organization.

Advice on the prevention, diagnosis and treatment of osteoporosis was given by experts from the BfO and the scientific section of the DGK, who were also available for individual consultation.

Concentrating on what people can do for themselves to prevent or manage osteoporosis, self-help groups gave presentations on how they can help the osteoporosis sufferer, and there was a demonstration of simple exercises. Teo and Rose, the eye-catching characters made familiar by the DGK to inform the public about healthy bones, enacted scenes highlighting the importance of calcium-rich nutrition and regular exercise for maintaining bone strength.

In the highlight of the Day, visitors heard the German TV stars Dunja Rajter and Frank Schröder explaining what measures they take in their daily lives to make sure their bones stay healthy. They earned standing ovations from an enthusiastic and appreciative audience.