



RESEARCH NEWS

Last year was a special one for osteoporosis, with two major meetings devoted to osteoporosis and to skeletal metabolism in general. The European Foundation for Osteoporosis and the International Federation of Societies on Skeletal Diseases organised the European Congress on Osteoporosis, attended by more than 4,000 experts from around the world. It was on this occasion that the two organisations merged to form the International Osteoporosis Foundation (IOF). At the end of 1998 the second joint meeting of the American Society for Bone and Mineral Research and the International Bone and Mineral Society took place in San Francisco, and again over 4,000 people participated.

Our understanding of the pathophysiology, diagnosis, prevention and treatment of osteo-

porosis has improved substantially in recent years as a result of numerous studies, conducted worldwide and often involving large numbers of volunteers. For example, more than 70,000 women are enrolled in the ongoing Nurses Health Study, which has already shown that vitamin K deficiency increases the risk of hip fracture. A Swedish study of over 30,000 men and women demonstrated a similar increased risk among diabetics. Another report at San Francisco confirmed that low calcium intake is associated with an increase in hip fracture risk, but that adequate vitamin D intake can compensate. This is due not only to the vitamin's effect on skeletal metabolism, but also to an independent beneficial effect on muscle function that reduces the risk of falls.

Molecular biology is proving a powerful tool for detecting abnormalities of skeletal meta-

bolism due to genetic polymorphism of genes such as collagen type 1 α 1, Sp1 or TGF β 1.

Therapy in patients with preclinical or established osteoporosis continues to improve. However, it is increasingly obvious that this research relies on investment by pharmaceutical companies. They play a critical role not only by financing studies, but also by providing personnel and expertise. An extremely high standard of quality assurance and control is guaranteed due to the close links between industry and research activities based at universities and other institutions. This has led to an explosion in the treatments currently available or under investigation: at the moment studies on estrogens or selective estrogen receptor modulators (SERMs), vitamin D and its metabolites, bisphosphonates, nasal calcitonin, and parathyroid hormone (PTH) fragment or entire molecule, are all underway.

Helmut Minne



Organisation

IOF Board:

Prof. Maurice Audran; Prof. Peter Burckhardt (ex officio); Prof. 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; Dr George P Lyrakis; Prof. Pierre J Meunier; Prof. Helmut Minne; Prof. Socrates Papapoulos; Prof. Jean-Yves Reginster; Prof. Johann Ringe; Prof. 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**; 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 Ortolani, **Italy**; Prof. Socrates Papapoulos, **The Netherlands**; Prof. Carlo Passeri, **Italy**; Dr Gyula Poor, **Hungary**; Dr Christine Pouliart, **Belgium**; Dr Jonathan Reeve, **UK**; Prof. Jean-Yves Reginster, **Belgium**; Prof. Johann Ringe, **Germany**; Prof. René Rizzoli, **Switzerland** (Chairman); Dr Christian Roux, **France**; Prof. Graham Russell, **UK**; Prof. Markus J Seibel, **Germany**; Prof. Alan Silman, **UK**; Dr Jan Stepan, **Czech Republic**; Dr Christian Wüster, **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*, GRIQ; **Germany:** Bundes-selbsthilfeverband für Osteoporose, Deutsche Gesellschaft für Osteologie, Deutsches Grünes Kreuz, 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 Society of Rheumatology, Lega Italiana Osteoporosi; **Japan:** Japan Osteoporosis Foundation, Japanese Society for Bone and Mineral Research; **Jordan:** Jordanian Osteoporosis Prevention Society (JOPS); **Korea:** Korean Society of Osteoporosis 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), SPODOM; **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; **Yugoslavia:** Yugoslav Osteoporosis Society.

*Associate member

IOF Committee of Corporate Advisors:

Abiogen Pharma srl, Asta Medica, Beckman-Coulter, Besins Iscovesco, Byk Gulden Lomberg Chemische Fabrik GmbH, Cassenne, Chiesi, Cilag International, Eli Lilly Italia SpA, Hoeschst Marion Roussel Inc, Hoffman-La Roche Ltd, Hologic Europe NV, IGEA srl, IRIS, 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, Procter & Gamble Pharmaceuticals Europe, Rhone Poulenc Rorer, Rotta Research Laboratorium, Schering AG, SmithKline Beecham, Schering 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-Orioni; **Funding Advisor:** Margaret Reilly Baer; **Assistants:** Véronique Chabanis, Silvy Grazioli, Claude Raynal.

Acknowledgements

Many thanks to all those who contribute to IOF News. IOF News is funded in part by Osteoporosis International (the number 1 orthopaedic journal), Eli Lilly, Merck Sharp & Dohme, Roche Pharmaceuticals and Teva.

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>

A WORLD WITHOUT OSTEOPOROTIC FRACTURES

Letter from the Editor



Dear Readers,

As you will know, last September saw the launch of the new International Osteoporosis Foundation.

IOF is now the largest grouping of people concerned with osteoporosis.

1999, the last year of this millennium, is thus also IOF's first full year of activity. IOF will continue to work like its predecessors EFFO and IFSSD at regional and national levels through its member societies. However, the new foundation is also looking forward to being able to play a much greater role on the international stage.

This requires commitment from all its members and, as with anything new, some changes. In this edition of IOF News we focus on recent organisational changes which will enable IOF to achieve its goals as it moves into the next century.

Yours sincerely

Helmut Minne

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

The vision of IOF is a simple but radical one: a world without osteoporotic fractures. IOF believes that healthier bones for all and an improved quality of life for osteoporosis sufferers are both realistic and achievable goals, and we will continue to campaign for this on an international level.

Action on a worldwide level has become easier now that IOF has a much wider geographical spread. There are 74 member societies in some 46 countries, and 40% of the Foundation's membership is currently outside Europe. When IOF held its first organisational meeting in Budapest on November 12–13 last year, it was agreed that the Founding Board needed to reflect more closely the international diversity of IOF's new constituency. The Board agreed to reduce its current membership to 10, creating space for 5 new Board members from a broader geographical spread. With this step, IOF is underlining its commitment to becoming a truly representative and international organisation for all those concerned about osteoporosis.

The Board also wants its membership to show that osteoporosis patients and their families form a large and important part of IOF's membership. In the future, the core of the Board membership will continue to be made up of people actively involved in

osteoporosis research and care, with a high level of scientific credibility. However, from now on non-medical community leaders will be included as well. Their work will vary with their particular interests and skills, and might range from political lobbying to consultancy to fundraising. I am confident that every Board member will make his or her own unique and significant contribution to the work of IOF.

IOF recognises that one of its key tasks is to raise the visibility of osteoporosis, which has aptly been called the "silent epidemic". One way of increasing public awareness is the use of famous faces as 'goodwill ambassadors'. Celebrities and royalty who are willing to give their time and energy to charity work can make a dramatic difference to public awareness and also to fundraising efforts (see article on p. 3). We are looking for more goodwill ambassadors: they should be people with an active interest in osteoporosis, from any walk of public life, and we welcome suggestions of appropriate personalities.

Pierre D. Delmas, MD, PhD
President of IOF

Founding Board 1998

European + 1 Middle East

- 15 members
- 3 ex officios



The Board 2000

Geographical mix reflecting membership

- 15 members
- 3 ex officios
- 6 non-medical community leaders

WORLDWIDE EFFORTS ARE BEING MADE TO IMPLEMENT THE "REPORT ON OSTEOPOROSIS IN THE EUROPEAN COMMUNITY" AT NATIONAL LEVELS

In the **UK**, the first ever government strategy on osteoporosis was launched on 25 June 1998 by Tessa Jowell, Minister for Public Health. The new policy document sets out targets for the management, treatment and prevention of osteoporosis for all health providers. Speaking at the Sixth Bath Conference on osteoporosis Ms Jowell highlighted the need to prioritise specific achievable targets, and described a range of initiatives being undertaken to implement the strategy. Among these are the approval of new clinical guidelines on osteoporosis by the Royal Colleges of Physicians, Surgeons, and Obstetricians and Gynaecologists; a summary of the guidelines' key messages has been provided for GPs and community nurses. Ms Jowell said the new government strategy emphasised the critical importance of partnership at every level in the fight against osteoporosis.

In **Sweden**, women MPs from all seven political parties signed a motion asking the Government what action it intends to take

on the eight recommendations made in the EU Report.

The **Netherlands** is one of the countries facing the heaviest burden from osteoporosis in the near future. During National Osteoporosis Week in November, the Dutch Osteoporosis Foundation (DOF) collaborated with one of the Dutch members of the EU Report Working Group, Prof. Wija van Staveren, to convey this message to the media and government. Over 40 million media contacts were achieved during this awareness week, an impressive figure for a country the size of the Netherlands. The Scientific Advisory Board of the DOF has been invited to join a multidisciplinary working group to update the current consensus on osteoporosis. They decided that patients were best helped by sending a non-medical representative to take part, reflecting the high profile and authority the DOF enjoys as the osteoporosis community's representative in the Netherlands.

All **Arab countries** will have access to an Arabic version of the EU Report within a few months.

A **Japanese** summary of the EU Report is soon to be published in the Japan Osteoporosis Foundation Newsletter.

In **Mexico**, the publication of the Report has been linked to a information centre that can deal with thousands of calls per day. Patient services will be tailored according to the requests received by the centre.

The full Report, in Danish, Dutch, English, Finnish, French, German, Greek, Italian, Portuguese, Spanish and Swedish, is expected to be available in March from the European Community Publications Sales Offices, price 15 Euro plus VAT.

For further information contact Messageries du livre SARL, 5 rue Railfeisen, L-2411 Luxembourg. Tel: +352 40 10 20, Fax: +352 49 06 61. E-mail: mdl@lu

The Report communications materials are available on the International Osteoporosis Foundation website: www.osteofound.org

World News

WHO AND OSTEOPOROSIS

EFFO, which was later to become IOF after its alliance with IFSSD, played a major part in the recognition of osteoporosis as a Public Health priority. It has been a long-standing partner of the World Health Organization's continued co-operation with academic and patients' associations. This was officially acknowledged during the European Congress on Osteoporosis in Berlin, when Dr. André Prost, Director of the Non-communicable diseases Division, evoked osteoporosis "as a priority health issue along with other major non-communicable diseases".

Within the next 2 years, IOF will further support WHO's efforts by developing its existing programmes. Further, it will initiate new activities at country and sub-continent level. These will be focused on raising public awareness and promoting scientific activities.

The European Union report on osteoporosis "Action for prevention", presented in Brussels on 10 June, 1998, will be a centre-point in this common strategy. IOF will

maintain its efforts to have it widely disseminated throughout the EU. It will develop appropriate activities at country level in order to get its main recommendations effectively implemented in a number of pilot countries. With the support of WHO, and based on its evaluation and epidemiological data, IOF will also initiate contacts in hardest-struck countries of other regions, so that they can make full use of available material to develop their own recommendations.

This continued co-operation should enable IOF and WHO to develop a full-blown plan of work based on the evidence of their fruitful activities at country level. This action build-up will make the move forward to osteoporosis prevention a daily reality.

EC PUBLIC HEALTH POLICY

Clive Needle MEP, rapporteur for Public Health Policy, invited IOF to comment on the European Commission's recent Communication on the inclusion of osteoporosis in public health policy to the year 2000 and beyond. IOF welcomed the publication of the document, which should

stimulate changes in EC policy that will improve health for all.

Building on the Communication's suggestion of a comprehensive, Community-wide system for collecting information on health, IOF noted that figures on fractures due to osteoporosis could be included in the existing Health Monitoring Program, providing data that will be invaluable in assessing actions taken to prevent and treat osteoporosis.

Acknowledging the Communication's emphasis on best practice in health care, IOF said that it is vital to agree on practical guidelines for the management of osteoporosis, using the principles of evidence-based medicine. It is just as important to implement them effectively. Here, the experience and flexibility of non-governmental organisations can be invaluable. IOF, for example, uses its multidisciplinary Committee of Scientific Advisors and network of national societies to promote medical innovations and improve osteoporosis care. IOF wants the vital role of NGOs, and the impact of public information activities such as awareness days, to be recognised.

FAMOUS FACES PUT OSTEOPOROSIS ON THE MAP

IOF's first organizational meeting in Budapest last November recognised the key role of celebrities and royalty in raising the public profile of osteoporosis. Some IOF member societies are extremely lucky in having goodwill ambassadors whose commitment and energy make an invaluable contribution to the worldwide fight against osteoporosis.

Camilla Parker Bowles became involved with the National Osteoporosis Society (NOS) of the UK after her mother died of the disease. In 1995 she organised an event which raised £20,000 for the Society, and in 1996 helped launch the NOS's Tenth Anniversary Appeal. Mrs Parker Bowles became a patron of the NOS in 1997. She gives generously of her time to fundraise privately through her contacts and to meet members, supporters and employees of the charity.



Mrs Camilla Parker Bowles (back row, extreme right) at the National Osteoporosis Society Tenth Anniversary

IOF Update

REPORT FROM THE COMMITTEE OF NATIONAL SOCIETIES

As the newly elected chairman of the Committee of National Societies, I am impressed by how dynamically it is evolving to reflect the new international character of IOF. Being international is the key to our future as a support and lobbying organisation. The Committee extends a warm and personal welcome to all those who have just joined us – the German Green Cross, Japan Osteoporosis Foundation, Jordanian Osteoporosis Prevention Society, Korean Osteoporosis Society (associate membership), Yugoslav Osteoporosis Society – and to the Saudi Osteoporosis Club, National Osteoporosis Foundation of South Africa and Swedish Osteoporosis Patient Society (ROP), who have become full members of IOF. We are very happy to accept membership applications from national societies worldwide.

Committee meetings are an important way of learning about other national societies and

Ilanit, the well-known Israeli singer, was the figurehead for a recent information booklet and television commercial campaign to draw attention to the fact that "fractures are not necessarily a natural part of the ageing process. Today osteoporosis can be diagnosed and treated, because bone can be treated."

Her Royal Highness Princess Sarvath El-Hassan, the honorary president of the Jordanian Osteoporosis Prevention Society, was guest of honour at a fund-raising gala dinner at the Amman Marriott Hotel in November. About 250 people attended the dinner, where lottery tickets were sold and the Princess herself made a generous donation to the work of the Society.

TARGETED SUPPORT

Most of the actual work of raising public awareness and acting on behalf of osteoporosis patients is done at the national level. So it is vital that patient societies, which range from large and well-funded operations to small groups of dedicated people, optimise their professional abilities. Targeted Support is a new empowerment program that aims to increase the professional skills of IOF member societies. The program will address the real needs of societies whatever their size or structure, by providing training and long-term professional consultancy focusing on specific, relevant issues.

their activities. Meetings also offer the opportunity to share information from around the world to help member societies achieve their goals. At our next meeting, the discussion will focus on how different countries implement bone densitometry measurements. To encourage non-European members to attend, 5 travel grants for each of this year's 2 Committee meetings are available.



P. Burckhardt

Prof. Peter Burckhardt,
Chairman of the
Committee of National
Societies

REPORT FROM THE COMMITTEE OF SCIENTIFIC ADVISORS

The Committee of Scientific Advisors represents the medical and scientific osteoporosis community. Membership is based on scient-



Israeli Singer Ilanit



Her Royal Highness Princess Sarvath El-Hassan at the gala dinner, with Prince Ali Jbn Navef (L) and Crown Prince El-Hassan (R)

Targeted Support grew out of the resoundingly successful workshops on professional skills held at the Worldwide Conferences in 1997 and 1998. The same professional facilitators will work intensively with national society staff to identify and meet their unique needs. For many societies, this will mean access to expertise they could not otherwise afford. The program will undergo rigorous evaluation by the national society and the facilitator: criteria for success will include demonstrated improvement in professional skills and an analysis of new activities.

ific merit. As well as undertaking vital research, the Committee advises on all information published or publicised by IOF.

To reflect its new international focus, the Committee is currently prioritising its work for the next 3 years. Some working groups, on epidemiology, genetic markers, bone diseases in children, rehabilitation, quality of life and training in the use of densitometry and ultrasound among others, have already been established. A Research Fellowship, worth up to Euro 45,000 and available to members of IOF national societies and Committee members, will encourage further progress. And at each Committee meeting, an evidence-based medical presentation will strengthen the link between research and clinical practice.



R. Rizzoli

Prof. René Rizzoli,
Chairman of the
Committee of Scientific
Advisors