

COORDINATED RESEARCH IS THE KEY IN THE FIGHT AGAINST OSTEOPOROSIS

The European Congress on Osteoporosis in Berlin (see front page) will include state of the art osteoporosis research going on in Germany. While in previous centuries attention was focused on the solitary scientist, today the trend is towards networks of research groups that allow multidisciplinary approaches and multicentre studies.

Willi Kalender (Erlangen), the 'father' of spiral computer tomography, developed the software for the quantitative computer tomography used by other research groups to assess bone mineral density. The European Vertebral Osteoporosis Study (EVOS) collaborated with my group from Berlin to analyse thousands of spinal x-rays from the study participants. Our use of x-ray morphometry built on the work of Gudrun Leidig and Helmut Minne, who in turn had been part of the group of Reinhard Ziegler (Heidelberg), one of the first osteologists in post-war Germany. Drs Leidig and Minne were also among the first to apply standardised questionnaires to assess the reduction in quality of life of patients with osteoporosis.

Markus Seibel, Heidelberg, is well known for his cutting-edge work in measuring specific markers of bone turnover, while Jan D Ringe, Leverkusen, is studying the efficacy of various drugs in patients with common or secondary osteoporosis. Having worked in San Francisco, Claus Gluer is now based at the University of Kiel, where he continues to improve the quality of quantitative ultrasound measurements.

These are some of the highlights of German osteoporosis research. Research in Germany is, however, only part of an international coordinated effort. To succeed it is vital to secure adequate funding so that coordinated research can be carried out across Europe. European research into osteoporosis should be part of the forthcoming 5th Framework Research Programme, so that knowledge can be shared and countries across the continent can benefit from each other's expertise.

Professor Dieter Felsenberg

Member of the EFO Scientific Advisory Board



EFO'S FIRST RESEARCH FELLOW

Dr Risto Honkanen, an epidemiologist, has become EFO's first Research Fellow. Based at the Research Institute of Public Health, University of Kuopio and Kuopio University Hospital, Finland, Dr Honkanen was one of the founders of OSTPRE, the Kuopio Osteoporosis Risk Factor and Prevention Study.

OSTPRE has been running since 1989 and aims to identify individual risk factors for and genes associated with low bone density, bone loss and fractures, and to investigate how risk and preventive factors interact. Dr Honkanen has amassed data from almost 12000 women who responded to a postal questionnaire in 1989 and 1994. Some of these women have since been enrolled in a randomized clinical trial investigating the effect of hormone replacement therapy (HRT) and vitamin D on bone and lipid risk factors. With the support of the EFO Fellowship, Dr Honkanen will be able to analyse the data acquired by OSTPRE, which will provide vital information on the fate of the individual threatened by osteoporosis.

Anna-Majja Nenonen, whose picture appears on the cover of the Report on Osteoporosis in the European Community, is one of the women enrolled in the study. Anna-Majja is committed to raising public awareness of osteoporosis. At the recent launch meeting/press conference for the report (see inside pages) she said,

"... every second year when I have fallen, I have broken some bones: my left forearm, left knee and left ankle. An intensive hug from a friend loudly crushed my bones ... I have lost 2-3 cm in height." She emphasised how much she had been helped by information from the research team and from the national osteoporosis society, and concluded: "People have to take responsibility for themselves."

With its first Fellowship, EFO is providing long-term support towards this.



Organisation

EFO Board of Trustees:

Pierre Delmas, President, **France**; Claus Christiansen, Secretary, **Denmark**; Herbert Fleisch, Treasurer, **Switzerland**; Pierre Meunier, Past President, **France**; Peter Burckhardt, **Switzerland**; Linda Edwards, John Kanis, **UK**; Socrates Papapoulos, **Netherlands**; Leo van Wersch, **France**.

EFO Scientific Advisory Board:

Belgium: Prof. Jean-Pierre Devogelaer, Prof. Piet Geusens, Prof. Jean-Yves Reginster; **Czech Republic**: Dr. Jan Stepan; **Denmark**: Dr. Claus Christiansen; **France**: Prof. Pierre Delmas, Prof. Pierre Meunier, Dr. Marie Christine de Vernejoul; **Germany**: Dr. Dieter Felsenberg, Prof. Claus Gluer, Prof. Helmut Minne, Prof. Johann Ringe, Dr. Markus Seibel; **Hungary**: Dr. Gyula Poor; **Israel**: Dr. Uri Liberman; **Italy**: Prof. Silvano Adami, Prof. Carlo Gennari, Prof. Sergio Ortolani, Prof. Mario Passeri; **Netherlands**: Dr. Paul Lips, Dr. Socrates Papapoulos; **Poland**: Prof. Roman Lorenc; **Sweden**: Prof. Erik Allander, Dr. Olof Johnell; **Switzerland**: Prof. Jean-Philippe Bonjour, Prof. Peter Burckhardt, Prof. Herbert Fleisch, Dr. René Rizzoli; **UK**: Dr. Juliet Compston, Prof. Cyrus Cooper, Prof. John Kanis, Dr. Jonathan Reeve, Prof. Alan Silman.

EFO National Society Board

Austria: Austrian Menopause Society, Austrian Society for Bone & Mineral Research, Selbsthilfe Gruppe Osteoporose*; **Belgium**: Belgian Bone Club, Belgian Royal Society of Rheumatology; **Czech Republic**: Czech Society for Metabolic Skeletal Diseases; **Denmark**: Danish Bone Society, Osteoporose foreningen*; **Finland**: Finnish Bone Society, Finnish Osteoporosis Society*; **France**: Groupe de Recherche et d'Information sur les Ostéoporoses, Association des Femmes contre l'Ostéoporose*; **Germany**: Bundeselbsthilfeverband für Osteoporose e.V., 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*; **Ireland**: Irish Osteoporosis Society*; **Israel**: Israel Society on Calcified Tissues Research; **Italy**: Italian Society of Mineral Metabolism, Italian Society of Rheumatology, Lega Italiana Osteoporosi, Società Italiana Osteoporosi; **Lebanon**: Lebanese Osteoporosis Prevention Society; **Lithuania**: Lithuanian Fund of Osteoporosis*; **Luxembourg**: Association for the Study of Bone Metabolism; **Netherlands**: Dutch Society for Calcium and Metabolism, Osteoporose Stichting, Osteoporose Vereniging; **Norway**: Norsk

Osteoporoseforening; **Poland**: Multidisciplinary Osteoporotic Forum, Polish Foundation of Osteoporosis; **Portugal**: Associação Nacional contra a Osteoporose, Portuguese Association of Osteoporosis, Portuguese Society of Metabolic Bone Disease; **Romania**: Romanian Club for Endocrinological Osteoporosis; **Russia**: Russian Association on Osteoporosis; **Saudi Arabia**: Saudi Osteoporosis Club*; **Slovak Republic**: Slovak Society of Osteoporosis and Metabolic Bone Diseases; **Slovenia**: Slovene Bone Society; **South Africa**: National Osteoporosis Foundation*; **Spain**: Fundación Española de Osteoporosis y Enfermedades Metabólicas, Sociedad Española de Investigación Osea y Metabolismo Mineral; **Sweden**: Riksföreningen Osteoporotiker*, Swedish Osteoporosis Society; **Switzerland**: Association Suisse contre l'Ostéoporose, Donna Mobile Arbeitsgemeinschaft Osteoporose Schweiz*; **UK**: Bone & Tooth Society, National Osteoporosis Society; **Ukraine**: Ukraine Association on Osteoporosis. (*Associate Member, **Corresponding Member)

EFO Corporate Advisory Board:

Abiogen Pharma s.r.l., Asta Medica, Boehringer Mannheim GmbH, Byk Gulden, Cassenne, Chiesi, Cilag Int., Hoechst Marion Roussel, Hoffman-La Roche Ltd., Hologic Europe, Hybritech Europe, IGEA s.r.l., Johnson & Johnson Clinical Diagnostics, Lilly Research Laboratories, Lunar, Merck KGaA, Metra Biosystems, MSD, Nestlé, Norland Medical Systems Inc., Novartis, Novo-Nordisk A/S, NV Organon, Osteometer Mediatech A/S, Ostex Europe Ltd., Pierre Fabbre Médicaments, Proctor & Gamble Pharmaceuticals Europe, Rhone Poulenc Ror., Rotta Research Laboratorium, Schering AG, Servier, Sunlight Ultrasound Technologies Ltd., Strathmann Ag & Co., Teva Pharmaceutical Industries Ltd., Yamanouchi.

EFO Staff:

Executive Director: Mary Fraser, Switzerland; **Executive Secretary**: Véronique Forterre, France.

Contact details for National Societies can be obtained from EFO web-site <http://www.effo.org> or via EFO secretariat in Lyon, tel: +33 472 914 177, fax +33 472 369052, e-mail: effolyon@net.asi.fr.

Editors-in-Chief Osteoporosis International: R. Lindsay (USA), P.J. Meunier (France)
Editor EFO News: H. Minne (Germany)

Acknowledgements

Many thanks to all those who contributed to EFO News. EFO News is supported by Osteoporosis International, the scientific journal of EFO 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, EFO News, EFO secretariat, 71 Cours Albert Thomas, F69003 Lyon, France, Tel: +33 472 914 177, Fax: +33 472 369 052, E-mail effolyon@net.asi.fr. EFO website <http://www.effo.org>

EFFO Patron



HM
Queen Silvia
of Sweden

Letter from the Editor



Dear Readers,

As a German, I am proud that Berlin, one of the most exciting cities in Europe, is hosting the European Congress on Osteoporosis. The event highlights the importance of osteoporosis as a public health problem in Germany and the need for increased recognition and resources for osteoporosis in Europe. This was underlined by the launch on June 10 of the European Community Report on Osteoporosis. In its honour, this is a special edition of EFFO News. The inside pages are devoted entirely to coverage of the launch meeting/press conference at the European Parliament in Brussels, and have been designed as a poster that you can use to spread the word about osteoporosis and EFFO!

Yours sincerely,



Professor Helmut Minne

EFFO 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

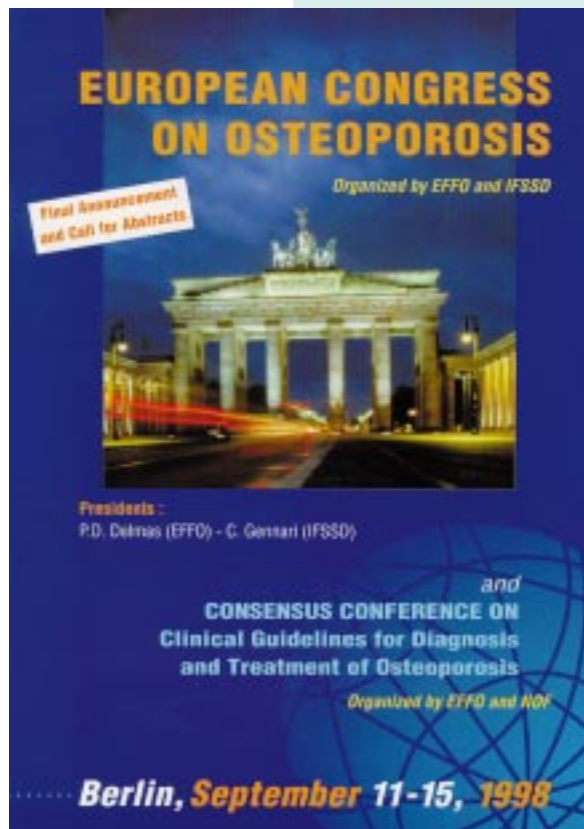
INVITATION TO BERLIN

Berlin, the city that is the new heart of Germany, will host the 1998 European Congress on Osteoporosis from September 11 to 15. Delegates from across the continent, including many from Eastern Europe, will congregate for this 4-day meeting aimed at all those concerned about osteoporosis.

The Congress provides the first opportunity for audiences at all levels to meet under one roof. Representatives of the scientific community, managers of osteoporosis societies, osteoporosis sufferers and members of the general public will be able to enjoy a programme that is custom-made for their particular area of interest and with ample opportunity for participants to mix. This innovative approach ensures the widest possible spread of quality scientific information and will educate researchers about the needs of osteoporosis sufferers.

The scientific programme offers 15 invited lectures, 34 oral presentations and 3 poster sessions, and runs from September 11 to September 15. The invited speakers will address such issues as the epidemiology of osteoporosis in women and men, and the appropriate use of effective medications. Poster sessions and satellite symposia will cover other aspects of the disease and its treatment in breadth as well as depth. Following the scientific programme, a Consensus Conference on Clinical Guidelines for Diagnosis and Treatment of Osteoporosis will take place on September 15.

Meanwhile, more than 1000 visitors from the Berlin area are expected to attend a Public Education Day on September 12, which aims to increase public awareness of osteoporosis and the activities of osteoporosis support groups and includes a performance by the music star Juliette Greco. The Day will also highlight the recommendations of the new European Union Report on Osteoporosis – Action for Prevention (see inside this edition of



European Congress on Osteoporosis organized by EFFO and IFSSD

EFFO News for more details). Finally, on September 13 and 14 the 4th Worldwide Conference of Osteoporosis Patient Societies will bring together over 100 participants for the exchange of ideas and experience, ensuring that the osteoporosis patient's voice is heard in Berlin.

For further information please contact EFFO Secretariat, 71 Cours Albert Thomas, F69003 Lyon, France, Tel: +33 472 914 177, Fax: +33 472 369 052, E-mail effolyon@net.asi.fr.

CORRECTION

On the front cover of the previous issue of EFFO News we said that "HRT is not reimbursed in France". This is not correct. HRT is reimbursed in France for osteoporosis. We apologise for this error!



LAUNCH OF THE REPORT EUROPEAN COMMUNITY

The report on Osteoporosis in the European Community was launched at a high-profile meeting and press conference at the European Parliament in Brussels on June 10, 1998.

Initiated by the European Commission at the request of the European Parliament, and managed and disseminated by EFO in collaboration with the German Green Cross (DGK) and the World Health Organization (WHO), it provides the first collection of extensive data on osteoporosis throughout the European Union. The report estimates that one in eight European Community citizens over the age of 50 will suffer a spinal fracture due to osteoporosis. The human costs of osteoporosis are not the only ones: over 3000 million ECU annually are spent on hospital health care alone. The report makes important recommendations for action by the European Union and member states to prevent, diagnose and treat osteoporosis.



Patients, politicians and scientists unite against osteoporosis. (From l to r, back row: Anna-Maija Nenonen, Augusto Fernando Vieira, Dr Anna Peckham, Mel Read MEP (Co-chair), Prof. François Blanchard, Dr Juliet Compston, Prof. Socrates Papapoulos; front row: Dr Henriette Chamouillet (European Commission Project Co-ordinator), Prof. Wija van Staveren, Prof. George Lyritis, Dr Quindio Correia MEP (Co-chair), Prof. Marianne Schroll, Dr Lars Elffors, Barbara von Stackelberg

Two members of the working group succinctly presented key messages from the report. Dr Juliet Compston from Cambridge University School of Clinical Medicine outlined its main



The clinicians discuss last minute issues! Dr Juliet Compston, UK, Prof. Pierre D. Delmas, EFO President, Prof. Socrates Papapoulos, EFO Trustee

conclusions, noting that in many countries the intake of calcium, availability of diagnostic procedures and clinical management of osteoporosis are substandard. Prof. Socrates Papapoulos from Leiden Medical Centre, who is also an EFO Trustee, summarised the report's recommendations. These emphasise the need to push osteoporosis as a major health priority throughout the EU and to foster coordination at local and European levels.

Three osteoporosis sufferers gave their view of the human toll of the disease. Dr Anna Peckham, a 28-year-old psychiatrist from Liverpool, said that osteoporosis can affect anyone of any age – it's not just an "old woman's" disease. Augusto Fernando Vieira from Portugal, an engineer, described how his osteoporosis was not correctly diagnosed for years. He stressed that support from family, friends and the national osteoporosis patient



Osteoporosis sufferers Anna-Maija Nenonen (Finland), Augusto Fernando Vieira (Portugal) and Anna Peckham (UK) tell their stories



society is vital for people living with osteoporosis. Anna-Maija Nenonen, a retired teacher from Finland, expressed her hope that the report will be taken seriously throughout the world and that governments collaborate with health and education professionals to take action.

WHO ATTENDED

Over 230 participants attended the launch meeting/press conference, including some of the "patients" featured on the front cover of the report: Inger Lundegardh, Carmen Sanchez, Hans van den Brink, Kjell Fensman and Edmund Bonn. European and national politicians present included Clive Needle MEP, Bernie Malone MEP, Dr D'Ippolito from the Italian Ministry of Health, Dr Escudeiro, Head of the Portuguese Department of Health, Dr Gil Lopez from the Spanish Ministry of Health, and Mr Hamedeh, a member of the Lebanese Parliament. Other participants represented osteoporosis and related associations and the

HIGHLIGHTS FROM THE LAUNCH MEETING

At the well-attended launch meeting/press conference, François Blanchard, President of the Report Working Group and Professor of Public Health, Epidemiology and Geriatrics at the University Hospital of Reims, gave a brief introduction to osteoporosis and to the report's international, multidisciplinary working group.

ON OSTEOPOROSIS IN THE - ACTION FOR PREVENTION

ng Bones
Fractures

Osteoporosis
Community
Prevention

that if I
nt the
life to
y, I had
nothing.

I'm worried about
the future. (NL)

Fishing, even
though it some-
times hurts, is
good therapy.
(DK)

ess and
I. (F)

around
She.
(I)



Far left: Padraig Flynn, Member of the European Commission, and Mel Read MEP enjoy the success of the launch meeting

Middle: Dr Caroline Jackson MEP

Right: Dr André Prost, WHO, explains that osteoporosis is a disease

media, including Spanish and Lebanese television, Radio France, Good Housekeeping, Le Monde, Le Figaro, and Reuters Online.

Some countries had particularly strong and enthusiastic representation, among them Spain and Portugal. The report and its launch were strongly supported by the Lebanese Osteoporosis Prevention Society, which sent a large delegation of politically active people and the media.

collaboration that made this report possible in the first place. For that same collaboration will ensure that it has real impact."

"Osteoporosis is being put on the political agenda as a health issue where European collaboration can make a real difference to the quality of life of thousands of people". That was the message of Dr Caroline Jackson, MEP and the daughter of an osteoporosis sufferer. Her speech highlighted areas where a Community dimension can be brought to concern about osteoporosis.

Dr André Prost, representative of the Director-General of the World Health Organization to the EU, said that the WHO classes osteoporosis as a disease rather than a 'natural' consequence of ageing. Although the report looks at the EU it is a model for other parts of the world where osteoporosis is not yet on the political agenda. It is strongly supported by the WHO and its Director General-Elect, Dr Gro Harlem Brundtland, well known for her activities to raise the profile of osteoporosis in Norway. Dr Prost called on everyone to take part in World Osteoporosis Day (WOD) on June 24 whose theme this year – appropriately – is "Government Action".

NEXT STEPS: WORDS INTO ACTION

The report places osteoporosis firmly on the European political agenda. More than this, its recommendations call for action. The key to action is for national societies, who represent scientists, clinicians and patients, to work together with politicians and ministries of health.

At the European level I appeal to MEPs and the European Commission to ensure that from now on, osteoporosis is included in all relevant

EC programmes. Osteoporosis should be addressed by the health indicators in the EU Health Monitoring Programme, for instance by counting the incidence of fractures throughout the whole of Europe to give an indication of progress being made in prevention and treatment. As Padraig Flynn said in his address to the launch meeting, the report should act as a trigger for the development of harmonised nutritional guidelines throughout the EU.

Research into osteoporosis can be carried out under the auspices of the forthcoming 5th Framework Research Programme for coordinated research across Europe (see Science Update).

Osteoporosis can be prevented, diagnosed and treated if there is the **will** to do so.



Mary Fraser: changing words into action

Mary Fraser
Executive Director, EFO

HOW TO ACCESS THE REPORT COMMUNICATION MATERIALS

- Follow the **link** from the EFO Website: <http://www.effo.org>
- Get the **summary report** from EFO and the German Green Cross
- Get the **full report** from the EC publication sales offices. The English report should be available within the next two months. The report is currently being translated into the 10 additional official EC languages which are expected to be available by the end of the year. For more information please contact your nearest European Community Publication Sales Office. A list of sales offices is available from the EFO website. The full report will cost approximately 15 ECU plus VAT.

German Green Cross (DGK), Tel. +49 6421 2930, Fax. +49 6421 163894, e-mail: kilian.verlag@kilian.de; EFO, Tel. +33 4 72 914177, Fax. +33 4 72 369052, e-mail effolyon@net.asi.fr



A full house for the launch meeting

MAKING THE REPORT WORK

Congratulating the members of the Expert Committee on a "splendid piece of work", Padraig Flynn, member of the European Commission and staunch supporter of EFO, hoped that the facts and figures presented in the report would inform all EU health programmes and trigger the establishment of health and nutritional guidelines throughout the EU. He highlighted the report as an aid for policy makers to improve care in the area of osteoporosis, and emphasised that, above all, the messages of the report must be turned into action. "Let's continue the cooperation and