

From the Editor



Dear Readers,
It has been gratifying to receive positive feedback on our first edition of "EFFO News". I believe that we are on our way to achieve one of our primary objectives "to promote widespread interaction." Continuing our quest, this Spring issue contains facts about hip fracture, news from national societies and the latest treatment developments.

Prevention of hip fracture, an issue covered in this Spring edition, is vital. Only by effectively preventing hip fractures can we prevent our fellow human beings from suffering severe pain, disability and premature death. In addition, this prevention would avoid a major socio-economic burden in the next decade.

When treating a disease such as osteoporosis, the patient's needs must be put first. Patient priority should not be forgotten when cost effectiveness is discussed in the health care community.

By allying the efforts of medical professionals, politicians and patient societies we can ensure the best value treatments in terms of costs and care.

Yours sincerely,

Professor Helmut Minne

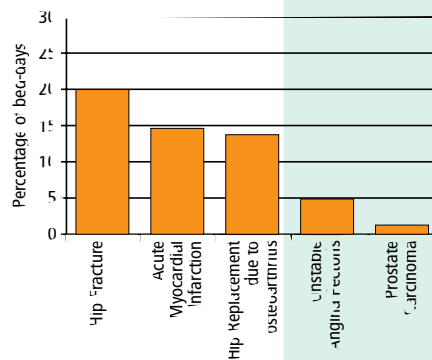
MAJOR SOCIO-ECONOMIC IMPACT OF HIP FRACTURE

Hip fracture is the most dramatic consequence of osteoporosis as over 90% of such fractures require surgical treatment, long-term hospital care and prolonged rehabilitation.

A large proportion of health care costs attributed to osteoporosis is associated with hip fracture. A recent Swiss study confirmed that acute-care hospital burden resulting from hip fracture was not only significant but also higher than other common pathologies of the elderly. The in-hospital care of hip fracture alone in Switzerland during a period of 12 months was crudely estimated at approx. Sfr. 20.5 million (~\$14.2 million), Sfr. 50,700 (~\$35,500) per fracture, exclusive of the additional major costs of nursing home care, outpatient care and social assistance.

Although the 1-year mortality rate for men was 35% versus 21% in women, women are more likely to require increased medical care leading to high overall acute and chronic health care costs. An improvement in ambulatory care in the short term and a reduction of hip fracture incidence by the prevention of osteoporosis in the longer term should be major priorities for decreasing the cost of health care in the elderly.

Hip fracture is a major cause of bed occupancy in acute-care hospitals



AMERICAN STUDY FINDS OSTEOPOROSIS TREATMENT COSTS SIGNIFICANTLY UNDERESTIMATED

Treating osteoporotic fractures is costlier than originally thought because previous estimates have overlooked expenditure associated with treating non-hip fractures, minority populations, or men, according to a study commissioned by the American National Osteoporosis Foundation (NOF). When projections were calculated for 1995 based on the more inclusive criteria, costs rose to \$14 billion from previous annual estimates of \$10 billion.

A separate report finds that more people may be affected by osteoporosis than originally believed. 28 million rather than 25 million Americans have or are at high risk from developing osteoporosis. The report projects that 41 million Americans may develop osteoporosis or low bone mass by 2015 unless steps are taken to prevent, detect and treat the disease.

"Americans need to stop viewing osteoporosis as an inevitable part of ageing and begin taking action at every age to begin reversing these numbers," says Robert Lindsay, NOF president.

EFFO Structure



RAPID EXPANSION OF EFFO NETWORK

Membership expanded by 40% in the last 12 months to a total of 43 national societies, including representation from 3 new countries - Ireland, Russia and Slovenia.

EFFO now represents 24 countries and more than 60,000 people. Corporate support has seen an increase of 10% with a total of 32 healthcare corporations as members of the Foundation. We are looking forward to a constructive collaboration with both the societies and supporters.

A database of over 1,000 contacts has been established to enable effective dissemination of information on osteoporosis to decision makers, journalists, healthcare professionals and individuals. An updated edition of "The Role of EFFO & Osteoporosis in Eu-

rope" booklet, which covers a wide range of related subject matter including the "Voice of the Osteoporosis Patient" and the latest facts & figures, is now available. The busy EFFO secretariat has appointed a new assistant, Gisèle Michon, who will be welcome help for Véronique Forterre. Gisèle has media, technological and language skills.

PATRON OF EFFO

H. M. Queen Silvia of Sweden is a patron of EFFO. Sweden has a comparatively high incidence of osteoporosis and active national patient and medical societies.

EFFO WEBSITE REACHES OUT: FEEDBACK REPORTS

Euro MP Anita Pollack mentioned our website in a press interview: "The idea of the website is to provide a resource for health professionals, patients and the public. It contains information and gives up-to-date scientific knowledge of the disease and information on support groups for sufferers." A web visitor from The Mayo Clinic in the USA sent a message: "Thanks for this new linkage with our European colleagues." Director of an osteoporosis centre, Michael T. Dimuzio said, "I hope that we can participate in services and educational activities that are critical to all of us involved in OP research, diagnosis and prevention." An individual Susannah Benson wrote, "Very helpful and useful info ... a friend's mother is apparently very ill with osteoporosis, so I said I'd see what I could find on the Internet about the disease."

Euro News

As Member of the European Commission I am kept well informed about osteoporosis and acknowledge that it is an important problem in public health. However, it is vital that others, not so well informed, should be made equally aware of how to prevent, detect and manage osteoporosis.

I met with EFFO in July 1996 and we discussed the importance of building up an osteoporosis network throughout Europe to heighten the awareness and understanding of osteoporosis at all levels and in all countries. A co-ordinated strategy towards the prevention and treatment of this disease is vital and EFFO has an important role in implementing this approach. By improving communication between the national societies the flow of information and implementation of initiatives between countries will be increased. The establishment of a dialogue between the EU and EFFO has also been an important first step in ensuring that osteoporosis is given due consideration for inclusion in EU programmes.

Since our meeting, EFFO has made notable progress by establishing a frequently visited website directing people to their respective national societies to receive support in their own language. "EFFO News" has also been launched which should further enhance the communication not only between societies throughout Europe but also between health care professionals, politicians and journalists, all of whom can further disseminate essential osteoporosis-related information.

I gladly lent my support to the first ever World Osteoporosis Day in 1996 which successfully increased the profile of osteoporosis as a health issue. The recognition of osteoporosis as a significant health issue within the EU is now evident with the official acceptance of the DGVF3 project "European Guidelines for Osteoporosis". This project covering eight major areas, demography and epidemiology, physiology and risk evaluation, prevention of falls, nutritional aspects, physical activity, environmental aspects, care and treatment and information, is a major step forward in the compilation of pan-European osteoporosis data and its publication in 1998 will have a great impact on future European action in this field.

However, osteoporosis still needs to be given a distinctive voice. I firmly believe that the appointment of a "celebrity spokesperson" would publicise osteoporosis effectively by capturing the attention of journalists as well as the public at large. Osteoporosis was described in a recent report published by The European Institute for Women's Health as a "Silent Thief"—we should aim towards breaking this silence by giving osteoporosis the maximum coverage possible. If osteoporosis became a household word throughout Europe, rather than an often misunderstood medical term, hundreds of thousands of fractures could be prevented.

Padraig Flynn

European Commissioner for Employment and Social Affairs

Developments

OESTROGEN ALTERNATIVES

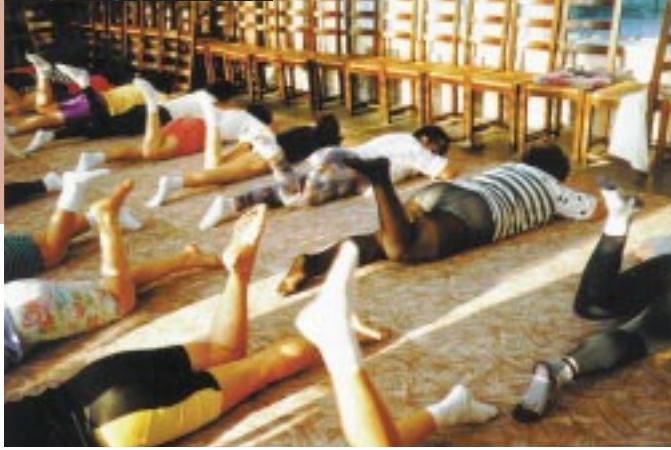
Oestrogen replacement therapy remains the gold standard in both the prevention and treatment of osteoporosis. However for those women unsuited to hormonal regimens, various alternatives are currently available or in development.

Bisphosphonates inhibit bone loss while allowing the formation of new bone of normal quality. Alendronate is the newest development in this group of drugs which is widely available. A recent study has shown that it can reduce the risk of new fractures (hip & spine) by about 50% in women with previous spinal fractures. Alendronate was recently recommended for approval in the USA for the additional labelling of prevention of osteoporosis for those women at risk and unable to take oestrogen. A study of alendronate in combination with ERT should be completed in September 1997.

Calcitonin, also widely available, is administered by injection or intranasally inhibiting osteoclast-mediated bone resorption and potentially reducing fracture frequency. Other advantages include its modest analgesic effect and good safety profile.

Parathyroid hormone (PTH) and fluoride salts have shown promise as agents capable of promoting bone formation. Co-therapy with PTH and resorption inhibitors such as oestrogen and bisphosphonates is under investigation.

New Services



Osteoporosis prevention gym class in Romania

OSTEOPOROSIS CLASSES

Thanks to Riksföreningen Osteoporotiker (ROP), four hospitals in Sweden now offer Osteoporosis Classes for newly diagnosed patients. Lasting 3½ days, all aspects of osteoporosis from diet to medical treatments are explained and discussed. By dedicating time to educating patients about their disease, the ROP hopes that quality of life will increase and less fractures will ensue.

The Fundatia Rheum-Care in Romania holds weekly meetings for the prevention of osteoporosis at gyms in Tirgu-Mures and Singeorgiu de Mures. These "Medical Gymnastic Groups" are run by physiotherapists with medical supervisors on hand for consultations. Leaflets in both national languages about suitable diet and exercises for the prevention of osteoporosis are also available.

Lobbying

UK PARLIAMENTARY ACTIVITY ON OSTEOPOROSIS INCREASES

Founded last year, the "All Party Group on Osteoporosis" (APGO) aims to alert both Houses of Parliament to the seriousness of the disease and to act as a forum for discussion on improvement of osteoporosis services. Since the advent of APGO, the first ever half hour open debate dedicated to osteoporosis took place in the House of Commons which prompted the government to pledge unequivocal support for local health authorities to take action to improve osteoporosis services.

ITALIAN SOCIETIES FUNCTION IN UNISON

The Italian Society of Osteoporosis and Metabolic Bone Diseases (SIOP) & Lega Italiana Osteoporosi (LIOS) have formed a working group to focus on social and political problems related to osteoporosis. SIOP has appointed an official representative in each region of Italy to give scientific advice and also promote guidelines directly to administrators responsible for regional health policy.

FOUNDING OF POLISH PATIENT SOCIETY

A group of doctors, scientists and technicians involved in metabolic bone disease established the Multidisciplinary Osteoporotic Forum in Poland in 1989. Over the past few years patient oriented activity has become increasingly important and last year this part of MOF was registered separately as STENKO, Polish Patient Oriented Society.

Fundraising

NATIONAL SOCIETY FUNDRAISING NEWS

A golf competition raised 3,800,000 lire for the Lega Italiana Osteoporosis in 1996.

In Slovakia the National Health Service has agreed to award SK 20 million for a patient education programme over the next 3 years.

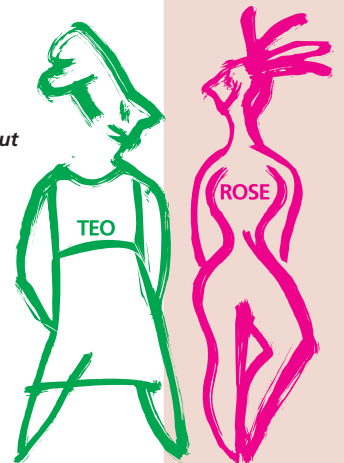
In the UK a National Draw with a new car as first prize made £89,000. The car was bought at cost price and tickets were sold through the 20,000 membership. A "Dinosaur Ball" was held in the Dinosaur Hall, complete with gigantic skeletons, at the Natural History Museum on Valentine's

TEO & ROSE HIT THE CAMPAIGN TRAIL

Kilian Verlag, a publishing subsidiary of the German Green Cross, has recently published two books: "Leitlinien Osteoporose", a summary of current osteoporosis information offering guidelines to medical practitioners and a patient's book "Osteoporose – Fragen & Antworten" answering most frequently asked questions. The books, costing DM 39,00 and DM 26,00 respectively, can be ordered from bookstores or directly from Kilian Verlag, im Kilian, Schuhmarkt 4, 35037 Marburg, Tel: +49 64 21/29 31 28, Fax: +49 64 21/16 38 94.

"Teo" and "Rose" (derived from osteoPOROSE) are the eye-catching symbols for the "Weeks for Healthy Bones" campaign throughout Germany. Teo is a cook who is keen on calcium and Rose an enthusiastic sportswoman. Appearing on posters, caps and buttons (or even in person), Teo & Rose entertained and informed the public during the campaign.

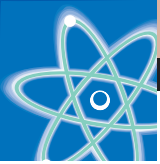
Teo and Rose informing the public about healthy bones



Day. A strong supporter of the NOS, royal companion Camilla Parker Bowles, has already raised £10,000 by hosting and organising a sculpture exhibition and dance performance for 200 friends.

GERMANY'S FIRST PATIENT SOCIETY CELEBRATED 10TH ANNIVERSARY

The foundation of the "Friends of the Kuratorium Knochengesundheit" club, which supports the Kuratorium Knochengesundheit patient society, has raised DM 36,000 with 300 new members each paying DM 120 annually. An admirable way for Germany's oldest patient society to begin its next decade.



Science Update

MEASURING QUALITY OF LIFE IN OSTEOPOROSIS: EFFO DEVELOPS SPECIFIC QUESTIONNAIRE

Although several instruments to measure quality of life have been developed over the last 15 years, it has become apparent that a disease-specific questionnaire may be a more effective measurement of quality of life in osteoporosis. The clinical consequence of osteoporosis is fracture but these fractures are not always accompanied by pain or disability. An EFFO Working Party has developed an initial questionnaire for quality of life in patients with established vertebral osteoporosis. It contains 48 questions in the following domains: pain, activities of daily living, jobs around the house, mobility, leisure and social activities, general health perception and mood. Translated into 8 languages, the "Qualeffo" has been designed for self-administration by the patient and is intended for use in clinical trials.

The first validation study showed adequate reproducibility and the questionnaire will now be adjusted. The EFFO Working Party is to continue by studying quality of life following distal radius fracture and hip fracture. Since the ultimate goal of treatment is to alleviate suffering and improve quality of life, measurement instruments are likely to play an increasingly important role in patients with osteoporosis.



Organisation

A warm welcome to 9 new EFFO member societies –

Austrian Menopause Society, in Germany Bundesselbsthilfverband für Osteoporose e.V and Deutsche Gesellschaft für Osteologie, Italian Society of Mineral Metabolism, Italian Society of Rheumatology, Norsk Osteoporoseforening in Norway, Portuguese Association of Osteoporosis, Russian Association on Osteoporosis and Slovene Bone Society.

Austria: Austrian Menopause Society, Austrian Society for Bone & Mineral Research; **Belgium:** Bédébone, Belgian Bone Club, Belgian Royal Society of Rheumatology; **Czech Republic:** Czech Society for Metabolic Skeletal Diseases; **Denmark:** Danish Bone Society; **Finland:** Finnish Bone Society, Finnish Osteoporosis Society; **France:** Groupe de Recherche et d'Information sur les Ostéoporoses, Association des Femmes contre l'Ostéoporose; **Germany:** Bundesselbsthilfverband für Osteoporose e.V, Deutsche Gesellschaft für Osteologie, German Society for Endocrinology, Kuratorium Knochengesundheit; **Greece:** Hellenic Society for the Study of Bone Metabolism; **Hungary:** Hungarian Society for Osteoporosis; **Ireland:** Irish Osteoporosis Society; **Israel:** Israel Society on Calcified Tissues Research; **Italy:** Italian Society of Mineral Metabolism, Italian Society of Rheumatology, Lega Italiana Osteoporosi, Societa Italiana Osteoporosi; **Lebanon:** Lebanese Osteoporosis Prevention Society; **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; **Russia:** Russian Association on Osteoporosis; **Slovak Republic:** Slovak Section Osteoporosis and Metabolic Bone Diseases; **Slovenia:** Slovene Bone Society; **Spain:** Fundacion Hispana de Osteoporosi y Enfermedades Metabolicas, Sociedad Espanola de Investigacion Osea y Metabolism Mineral; **Sweden:** Riksföreningen Osteoporotiker, Swedish Osteoporosis Society; **Switzerland:** Association Suisse contre l'Ostéoporose; **UK:** Bone & Tooth Society, National Osteoporosis Society.

Contact details for National Societies can be obtained from EFFO web-site <http://www.effo.org> or via EFFO secretariat in Lyon.



Round the World

UNIVERSAL DISCRIMINATION AGAINST FEMALE DISEASES

As recently noted in the New England Journal of Medicine, "explicit sex discrimination in health insurance is unjustifiable," yet evidence of it can be seen in the USA and in Europe.

A US study of the 10 most common illnesses in persons with Medicare and Medigap coverage found that illnesses with the lowest reimbursement were more common in women and those with the highest more common in men. A manifestation of this could also be seen in Southern Germany where mammographies and bone scans were in serious danger of being cut from regular reimbursement.

The New England Journal claimed that "men's greater seniority as insurers and employers may explain why health insurance policies fit men's needs better than women's." Although women live longer than men, the quality of life of those extra years is burdened by conditions such as osteoporosis which are preventable and treatable. Given that men and women have different life spans, medical needs and social roles, the present health care system should be examined in relation to gender. Men and women must have equitable health care policies to avoid surging costs as the population gets greyer.



Controversies

NO SUBVENTION FOR PROTECTIVE PREVENTION

It is routinely accepted that the risk of hip fracture can be reduced therapeutically by the prevention of bone loss or therapeutic increase of bone mass, but this improvement in bone strength cannot prevent falls and subsequent trauma to the hip. Experimental studies have shown that soft tissue covering the hip may influence energy absorption during a fall, reducing the risk of hip fracture.

Hip protectors have recently been introduced to prevent hip fractures and results from two studies in nursing homes show that use of hip protectors reduced the annual rate of hip fracture by 50%.

Despite their relatively low cost (DM 100/ \$59) German health insurance companies do not reimburse for hip protection, citing their "preventive" use. However, on comparing the current health care cost of \$44,000 per hip fracture to \$177 for 3 pairs of hip protectors, it would appear that they are remarkably cost effective.

Acknowledgements

Many thanks to all those who contributed to EFFO News. EFFO News is supported by Osteoporosis International, the scientific journal of EFFO 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, EFFO News, EFFO secretariat, Pavillon F, Hôpital E.Herriot, F69437 Lyon Cedex 03, France. (Tel +33 472 11 74 72, fax +33 472 117 494, E-mail: mfraser@effo.org). EFFO website <http://www.effo.org>