

EFFO News

EUROPEAN FOUNDATION FOR OSTEOPOROSIS & BONE DISEASE

From the Editor



Dear Readers,
The bad news is that millions of European women and men suffer from osteoporotic fractures. The good news is that if we used our current resources properly, more than 50% of these fractures could be avoided.

These facts must be brought to the attention of the European population, to physicians, to health administrators and politicians. I believe that the EFFO newsletter will play a critical role in the communication of important information and promote wide-spread interaction between our ever expanding audience.

Thus I take great pleasure in introducing you to our first edition of EFFO News. It is packed with topical information from many of our member societies plus a personalised contribution from a member of the European Parliament and the latest results from the European Prospective Osteoporosis Study.

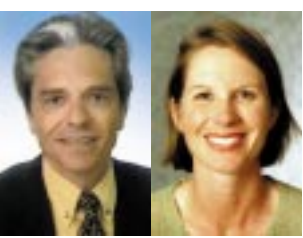
Yours sincerely,
Professor Helmut Minne

Contents

EFFO Update January 1997	1
Fundraising Basic Principles	1
Facts & Figures Osteoporosis on the Increase	2
Euro News High Profile for Osteoporosis	2
Lobbying Societies Successes	2
New Services Innovations throughout Europe	3
Developments Discriminatory Cost Cutting	3
Science Update Latest EPOS results	4
Organisation List of Societies, Existing and New	4
Round the World Women's Health Review	4
Controversies Disease Confusion	4

EFFO HERALDS ITS 10TH BIRTHDAY WITH NEWSLETTER LAUNCH

Welcome to the debut edition of EFFO newsletter. It has been produced in response to many requests from our member patient societies to provide a pan-European means of communication.



President, Pierre D. Delmas
Executive Director, Mary Fraser

"EFFO NEWS", a quarterly publication, aims to facilitate the exchange of news and ideas between EFFO national societies and to provide a lobbying tool for use with decision makers. To fulfill these aims your feedback and ideas are vital – we look forward to receiving them!

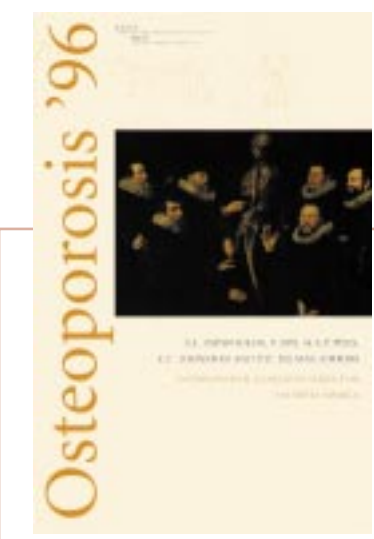
We are delighted to announce that Professor Helmut Minne has accepted the role of editor, particularly as the newsletter was originally his idea. Professor Minne, figure head of the Kuratorium Knochengesundheit, a large patient society in Germany, is acutely aware of all the opportunities and issues facing osteoporosis patient societies and we are grateful for his valuable collaboration. We would also like to

thank Springer for all their help in printing the newsletter.

For those unfamiliar with EFFO, it is a collaboration between patient, medical and research societies, healthcare professionals and the health industry to improve the management of osteoporosis. 1996 was an eventful year for EFFO with not only the employment of its first Executive Director and the launch of its own Internet Website but also the 1996 World Congress on Osteoporosis, jointly organised by EFFO and American National Osteoporosis Foundation, attended by 4,000 scientists from 60 countries across 5 continents. This year, EFFO's 10th birthday, will see the re-launch of EFFO with its new broader audience, namely journalists and decision makers as well as healthcare professionals. Together with the publication of this newsletter we hope to achieve our mission to unite and coordinate the most effective management against osteoporosis in Europe.

Best wishes for 1997!

All members of EFFO will automatically receive a limited supply of newsletters but for those who wish to receive a copy directly, this issue includes a card to order the newsletter and to subscribe to Osteoporosis International, the scientific publication of EFFO and the American National Osteoporosis Foundation.



The Proceedings of the 1996 World Congress on Osteoporosis have been published by Elsevier Science in the Netherlands. The volume is divided into seven sections covering all aspects of the disease plus state-of-the-art reviews and selected papers. "Osteoporosis '96" costs Dfl. 330 and can be ordered direct from Elsevier Science tel: +31 20 485 3757, fax: +31 20 485 3432.

OSTEOPOROSIS ON THE INCREASE

Already a major healthcare issue, osteoporosis is in danger of becoming one of the biggest challenges to the healthcare industry.

The current risk of fracture of the hip, spine and forearm for a 50 year old European woman is estimated at greater than 30%. On a global scale 2.5 million osteoporotic fractures occur every year, 1.7 million of which are fractures of the hip region, the most dangerous type of fracture in terms of reducing lifespan. As the proportion of the elderly population increases so does the frequency of osteoporotic fractures. Without appropriate preventative measures hip fractures are set to increase by 60% over the next three decades. Doctors, governments, women and men

themselves should take action now to reduce the overall level of risk.

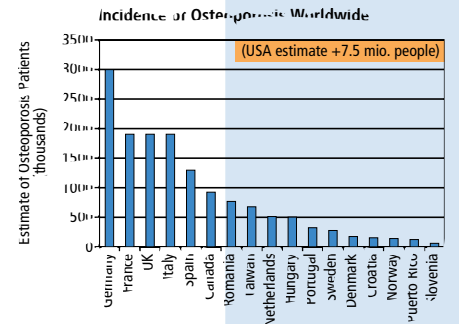
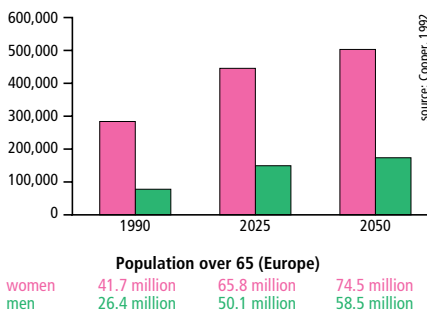
Feedback from EFFO questionnaire confirms European geographical trend.

According to the national society responses to the EFFO questionnaire on the incidence of osteoporosis in their respective countries, the incidence of hip fracture decreases from north to south. The highest incidence of osteoporosis was recorded in Sweden with 1 in 2 women and 1 in 4 men. Moving southwards the frequency in the UK, Germany and Spain is 1 in 3 women. In more detail, 1 million males and 2 million females suffer at least one vertebral fracture in Germany, in the UK the data translates into a fracture due to osteoporosis every 3 minutes. In Ireland approximately 65% of women have bone mineral density more than 2 standard deviations below the mean by the age of 70.

13,679 in 1995. Even in countries where exact data is not yet available, osteoporosis is already a major healthcare issue. Slovakia estimates that 6,000 hip fractures occur per year and about 12% of men and women suffer from vertebral deformity.

Despite geographical differences and the difficulty in assessing exact frequency, the collation of national statistics is essential in the ongoing quest to develop effective programmes for the prevention and treatment of osteoporosis. Many thanks to all those who completed the feedback questionnaire.

Projected increase in incidence of hip fractures in European woman and men 65 and over, 1990-2050



Euro News

HIGHER PROFILE FOR OSTEOPOROSIS IN EUROPEAN UNION

For far too long osteoporosis has been a 'hidden disease' - with many people suffering in silence. My own mother suffered terribly from osteoporosis, but it was only diagnosed as such shortly before her death. I am very pleased that at last this crippling disease is being given a higher profile, and I greatly value EFFO's active role in this.

It is striking how widely the levels of knowledge and information about osteoporosis vary across the European Union. Reducing these discrepancies, both within and between countries is vital. I think that the European Union can, and should, commit itself to coordinating the exchange of information and transmitting it to the European public at large. The European Commission could also assist with the costs of adapting, translating and distributing the excellent material originating from national associations and I shall continue to make strong representations to the Commission to this effect. The challenge is to put our wealth of

scientific knowledge about osteoporosis to practical use by greater information dissemination. The EU should also ensure that funds already allocated to health are properly targeted. I know that EFFO is attempting to achieve just that and significant progress is being made.

The "Health Promotion and Disease Surveillance" unit of the European Commission organised a first meeting with experts on osteoporosis in February 1996. Consequently eight working groups have been set up to compile information which should culminate in a report in early 1998. This vital report will act as the basis for future European action in this field and I will do my best to ensure that it is produced and taken seriously. Finally I would like to express my strong admiration for those committed individuals campaigning for better awareness of osteoporosis.

Thank you for allowing me to welcome the publication of this new newsletter, and I wish EFFO every success in the future.

Dr. Caroline Jackson
Member of the European Parliament

Lobbying

RECENT SUCCESSES

Osteoporosis has enjoyed great exposure at both the Swedish and British Houses of Parliament. The Swedish Society, ROP, was recently involved in raising a motion in the Swedish Parliament asking for a complete survey of the osteoporosis situation. Signed by members from each of the seven parties in the Swedish parliament, this motion inspired five younger Social democratic MPs to raise another about the importance of osteoporosis. Both motions will be dealt with in the Standing Committee of Social Affairs, probably during the spring session. In the UK, the NOS triumphed in setting up an All Party Osteoporosis Group in the House of Commons and House of Lords involving at least 100 MPs.

Fighting for osteoporosis support was recently on the political agenda for the Kuratorium Knochen-gesundheit. Budget cuts were threatened for self support groups throughout Germany, but, assisted by the Knochen-gesundheit, these groups took immediate action by contacting their local and federal politicians. Their endeavours paid off with a cancellation of the planned cuts.

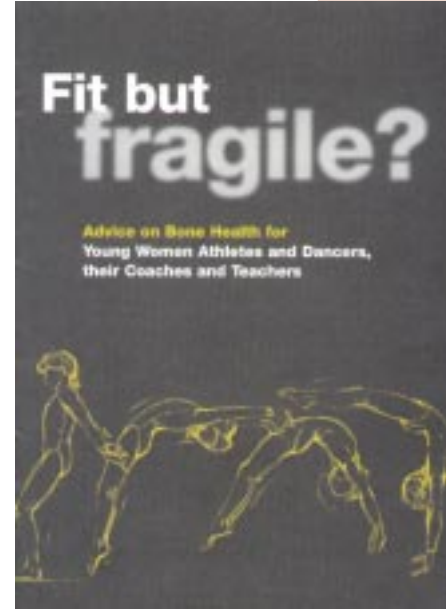
WEALTH OF INNOVATIONS ALL OVER EUROPE

A few highlights from national societies:

- Recognising the power of the press, an award for osteoporosis journalism has been announced in Spain.
- The 1996 German Osteoporosis Prevention Week successfully opened in Dresden in October 1996 and was followed by 250 meetings.
- The latest new societies, Czech Osteoporosis Foundation and Irish Osteoporosis Society are publishing their first booklets.
- In Italy calcium-rich recipes have been donated by 3 professional chefs to produce a cookbook

appealing to the Italian palate. An osteoporosis freephone hot-line is planned for the near future.

- You don't have to be too thin to win – In the UK a booklet aimed at young athletes and dancers entitled "Fit but Fragile" was successfully launched in Autumn 1996 with Princess Anne in attendance.
- "Because I can't read English or Urdu, leaflets aren't much use. It would be nice to have a video". The Asian Communities in the UK have an increased risk of osteoporosis but find help hard to find. Recognising the need for culturally sensitive and linguistically appropriate information, the NOS commissioned a study establishing what sort of educational materials met their needs.



Bone Health Booklet for Athletes and Dancers from the UK

The EFO newsletter welcomes any information on new services offered by the National Societies, send us your latest ideas!

Fundraising

COMMIT SPONSORS TO YOUR CAUSE

Close to our hearts, fundraising is a fundamental part of our activities. Richard Tallontire from the International Fund Raising Group, a non-profit based organisation, shared a few of his basic principles.

- Rather than budgets and balance sheets, fund raising is about people and their needs,
- Use language people will understand, avoid jargon, communicate vividly and speak about real needs in human terms.
- Treat supporters as friends, show interest in them, make them members of a large team; take opportunities to meet supporters face to face.
- Don't be afraid to ask – you won't get support unless you make it clear what kind of support you need.
- You are the Ambassador: what kind of an impression do you give – efficient, committed, effective? Or disorganised, uninterested and incompetent?
- It is vital always to be honest, open and truthful
- The easiest way to lose a supporter is to fail to thank them. The second easiest way is to thank them too late.

In the next issue we will be featuring national fundraising activities, so please let us know of any recent successes.

Developments

HEALTHCARE FUNDING

A worrying trend, already evident in Sweden, Germany and Italy, is cost containment by health administrations and insurance agencies.

These reductions particularly affect the long term health prospects of those most dependent upon the state, namely the elderly and the handicapped, which encompasses most osteoporosis patients.

In Sweden this has been manifested in a future reduction in state subvention of pharmaceuticals meaning that patients will have to pay considerably more out of their own pockets. Some osteoporosis patients will undoubtedly become reluctant to accept effective but expensive pharmaceutical treatments. Similarly the most effective drugs for osteoporosis treatment are not covered by the National Healthcare system in Italy, forcing patients to pay the total cost of their treatment. Osteoporosis diagnosis is also under threat as bone mass measurement reimbursements are currently being questioned in Germany.

The National Societies are doing their best to respond to these cost-cutting measures by stressing that prevention and early detection is the most efficient way to reduce the need for expensive hospital care, rehabilitation and social services.

PROGRESS IN PACKAGING

The UK National Osteoporosis Society has joined forces with the ABPI (Association of British Pharmaceutical Industries) on a Patient Information Pack Initiative aiming to provide clearer patient information plus the Society's details on the package insert as a source of support and advice.



Science Update

FIT AND FERTILE IS BEST FOR BONES

Dr. Jonathan Reeve, EPOS project co-ordinator has updated us with the latest results of the European Prospective Osteoporosis Study. A large multi-national study of osteoporosis in men and women aged 50 years or older, EPOS has recruited over 17,000 patients to 36 European Centres in 18 countries.

The prevalence study revealed that vertebral deformities were almost equally prevalent in both sexes overall. However, at the age of 50 deformities were less prevalent in women. By the age of 80 the situation was reversed with women having suffered more deformities. These data suggest that in men not all vertebral deformities are related to osteoporosis.

Results of a half-hour interview with subjects showed that in women a long period of fertility and physical activity was protective against vertebral deformity. A moderate amount of physical activity in men offered similar protection but arduous exercise was detrimental. Another protective factor was body fat. Plumper than average appears to be the healthiest size for both men and women.

Future plans include a 4-stage follow-up of the subjects and the close liaison with other European studies of hip fracture and financial support has been requested from the European Commission. By completing and correlating the many studies on the epidemiology and impact of osteoporosis the scene should be set for the development of more effective interventions directed at preventing fractures or at least minimising their impact on the individual.



Organisation

A warm welcome to new patient societies - the Finnish Osteoporosis Society, AFcOP in France, the Irish Osteoporosis Society (whose patron is the President of Ireland), APOROS in Portugal, Riksföreningen Osteoporotiker in Sweden and the Czech Osteoporosis Foundation.

Membership of EFO is increasing, as we go to press, EFO has 36 national societies as members (listed below):

Austria: 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 & Tooth Society; **Finland:** Finnish Bone Society, Finnish Osteoporosis Society; **France:** Groupe de Recherche et d'Information sur les Ostéoporoses, AFcOP; **Germany:** 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:** Lega Italiana Osteoporosi, Societa Italiana Osteoporosi; **Lebanon:** Lebanese Osteoporosis Prevention Society; **Netherlands:** Dutch Society for Calcium and Bone Metabolism, Osteoporose Stichting, Osteoporose Vereniging; **Norway:** The Norwegian Society for Bone Research; **Poland:** Multidisciplinary Osteoporotic Forum, Polish Foundation of Osteoporosis; **Portugal:** Associação Nacional contra a Osteoporose, Portugese Society of Metabolic Bone Disease; **Slovak Republic:** Slovak Section Osteoporosis and Metabolic Bone Diseases; **Spain:** Fundacion Hispana de Osteoporosi y Enfermedades Matabolicas, Sociedad Espanola de Investigacion Osea y Metabolism Mineral; **Sweden:** Swedish Osteoporosis Society, Riksföreningen Osteoporotiker; **Switzerland:** Swiss Association against Osteoporosis; **UK:** Bone & Tooth Society, British Menopause Society, National Osteoporosis Society (Princess Anne is the official 20,000 member).

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



Round the World

RECENT HEALTH REVIEW HIGHLIGHTS WOMEN'S HEALTH

"Strengthen the role of patient support groups" and "fund further research" were amongst the recommendations for osteoporosis management in the report recently produced by the European Institute of Women's Health entitled 'Women in Europe towards healthy ageing – a review of the health status of mid-life and older women'.

The need for health promotion and education measures in four health areas (coronary heart disease, cancer, osteoporosis and depression) was emphasised and, in the case of osteoporosis, the review advocated "raising awareness amongst women, healthcare professionals, policy makers throughout Europe about the human and economic costs of osteoporosis-related fractures". Commenting that osteoporosis knows no boundaries, the European Union was encouraged to share resources and information. The review concluded that "preventing osteoporosis is of the greatest urgency both for quality of life and economic reasons".

Help implement these recommendations by distributing this review to influential members of your healthcare community. Copies are available from Peggy Maguire, Director General, EIWH, tel: +353 1 6766717, fax: +353 1 6766740. The osteoporosis recommendations and conclusions can also be accessed on the EFO web site, <http://www.effo.org>.



Controversies

OSTEOPOROSIS VERSUS OSTEOARTHRITIS, THE COMMON MISUNDERSTANDINGS

The confusion between osteoporosis and osteoarthritis can delay the diagnosis and management of osteoporosis, with dire consequences. A recent US nationwide survey revealed that 75% of Americans are uncertain of the differences between the two and do not realise that osteoporosis usually presents as a silent disease. This results in osteoporosis patients waiting for recognisable symptoms, such as pain, by which time there may have been excessive bone loss. Even in Europe, where superficial awareness of osteoporosis is high (90%), over 50% of women are unsure of the symptoms.

GOOD PROSPECTS FOR ULTRASOUND IN OSTEOPOROSIS

Quantitative ultrasound (QUS) is a portable, quick and inexpensive method of bone mass assessment which is non-invasive and involves no radiation. Although dual x-ray absorptiometry (DXA) is the current preferred method for identifying individuals at risk, it is not readily portable and can be expensive. With such a considerable potential for wide-spread clinical application of QUS, studies are underway to assess its value as a diagnostic tool for osteoporosis. A recent French study (EPIDOS) has already proved QUS to be as effective as DXA at predicting hip fracture risk in the very elderly. It is still early days but the future for QUS looks promising.

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, 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). EFO website <http://www.effo.org>