

Letter from the Editor



Dear Readers,

Why should we bother about osteoporosis? I believe the answer to this question lies in three things: justice, economy and common sense. Justice is for the patients, who suffer disability and pain that can match that of a heart attack;

The economic argument asks why we should provide more hospital bed days annually for hip fractures, a preventable complication of osteoporosis, than are needed for heart attack and stroke patients combined;

And it is only simple common sense to provide the tools for the earliest possible diagnosis of osteoporosis, when treatment of the late complications cost more than 3 billion Euros per year in Germany alone.

These arguments reinforce the need for more awareness and action. This is why IOF wholeheartedly supports initiatives such as the International Press Conference on October 11 in Lyon (see this page), as part of this year's World Osteoporosis Day.

Yours sincerely

Helmut Minne

IOF Vision

The vision of the International Osteoporosis Foundation is a world without osteoporotic fractures

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

IOF Goals

- Nurture and enlarge the IOF network of member societies worldwide
- Promote medical innovation and improved care
- Expand IOF partnerships with organisations working on similar or complementary issues and projects
- Lobby for policy change in all countries through implementation of the recommendations of the Report on Osteoporosis in the European Community – Action for Prevention, and other appropriate policy instruments

UN SECRETARY KOFI ANNAN MEETS BONE & JOINT DECADE 2000-2010



Mary Fraser, IOF Executive Director, presents Kofi Annan with information on the Bone and Joint Decade.

Since March this year, when Mary Fraser was Sunanimously elected to the Steering Committee, IOF has represented the interests of the osteoporosis community in the Bone and Joint Decade 2000-2010. On May 27th, the Steering Committee was delighted to have the opportunity to meet the UN Secretary

General Kofi Annan in the course of its gathering in Lund. The Committee was able to present the Secretary General with a letter and extensive information on the aims and plans of the Bone and Joint Decade. Although no official answer was requested from Kofi Annan, the presentation was well received and the message referred to his staff for review.

Such meetings enhance the Decade's worldwide credibility, and thus its opportunities to raise the profile of bone diseases including osteoporosis. It is equally crucial to obtain government support, whether in the form of a Presidential statement, an endorsement of the Decade's official Declaration, or simple recognition by a Ministry of Health. Nine governments now officially support the Bone and Joint Decade; the latest to do so are the United Kingdom, the Netherlands and Bulgaria.



JOINT WHO-IOF LAUNCH OF WHO GLOBAL STRATEGY FOR OSTEOPOROSIS

A further encouraging sign of top-level interest in osteoporosis is the launch of the World Health Organization's Global Strategy for Osteoporosis. This aims to improve the diagnosis and care of osteoporosis patients throughout the world, with a particular emphasis on developing countries. The cornerstone of the project is the preparation of a master document on osteoporosis management and prevention, which will be used as the basis for a "Practical Guide for Osteoporosis Management" aimed at primary care physicians throughout the world.

Members of the task force charged with preparing the master document have met periodically since July 1998. In June this year they gathered at the headquarters of the WHO in Geneva, where they decided to publish an interim report summarising the document's chapters and preliminary recommendations. This will appear in IOF's scientific journal Osteoporosis International in October 1999, to coincide with the World Osteoporosis Day on October 20. Its publication is co-sponsored by

WHO and endorsed by the National Osteoporosis Foundation of the USA. The master document itself should be available in April 2000.

IOF welcomes the efforts of WHO in taking osteoporosis seriously as a global problem. However, we must remain aware that to be fully effective this concern must be translated into real action by national governments.

An international Press Conference to launch the Global Strategy will be held on Monday October 11, 1999, at the Hilton Lyon, 70 quai Charles de Gaulle, Lyon. Journalists will hear Prof Pierre Delmas, President of IOF, explain IOF's role in promoting osteoporosis prevention and treatment worldwide. Other speakers will include Dr Gro Harlem Brundtland, Director General of WHO (to be confirmed), who will be invited to have her bones tested at the clinic of Professors Delmas and Meunier.

Journalists interested in attending should contact the IOF International Secretariat, Lyon, France, Tel: +33 4 72 43 05 04, Fax: +33 4 78 17 74 07.

An astonishing 15,000 people took part in a "fun run" organised by the Lebanese Osteoporosis Prevention Society (LOPS) on May 9. In brilliant sunshine, and heat that had many walking rather than running, people of all ages covered the 5 km route from the capital. Free drinks, including milk, were available and many people took the opportunity to donate money or buy baseball caps or T-shirt souvenirs.

Dina Azar, a former Miss Lebanon, and Elie Mouchantaf, a well-known Lebanese basketball player, showed their support by starting the fun run. Also taking part were Information Minister Anwar Khalil and Education and Culture Minister Youssef Beydoun, who said "Lebanon is united here



by people from the south to the north who have come to walk together to build stronger bones."

LOPS founder Ghassan Maalouf stressed the importance of events like this in public education about the "silent disease". Wheelchair-user Mohammed Shammou and other members of the Lebanese Sports Organization for the Disabled, played basketball at the start of the fun run and said, "I think this type of event should be held on a regular basis."

Celebrities offer support. Dina Azar, a former Miss Lebanon and Elie Mouchantaf, national basketball player join with others at the start of the fun run (front line second and third from the left).

TARGETED SUPPORT PROGRAM

The worldwide osteoporosis movement derives its strength from the energy and abilities of its individual national societies, who do most of the work of raising public awareness and acting on behalf of osteoporosis patients. Targeted Support, a new empowerment program, was created to help the smaller IOF national societies become more effective and optimise their professional abilities.



Targeted Support grew out of special workshops on professional skills that were held at the Third and Fourth Worldwide Conferences of Osteoporosis Patient Societies in 1997 and 1998. This year, with the help of funding from Roche Pharmaceuticals, IOF has been able to offer Targeted Support to five member national societies in Hungary, Sweden, Mexico, Japan and South Africa. The range of countries illustrates IOF's increasingly international focus. Professional facilitators have provided in-country visits, workshops, briefings and skills support, all focusing on specific, relevant issues identified in collaboration with the national societies.

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Focusing on the countries outside Europe, what have been the results so far?

Paul Sochaczewski, IOF Communications Advisor, visited Mexico (Comite Mexicano para el estudio de la osteoporosis, COMOP) and South Africa (National Osteoporosis Foundation). It was Mexico's second visit and was dedicated



to reviewing and finalising plans for World Osteoporosis Day 1999 and 2000. As a result, messages have been clarified under the overall concept of Muévete ("move yourself"), and 3 objectives for WOD 1999 identified. These were to send a representative of COMOP and of the Mexican government to the joint WHO-IOF Global Strategy launch, increase public awareness with activities linked to exercise, and encourage densitometry owners to stage an "open house" on WOD. COMOP thanked IOF for "the excellent program of public support ... I want to emphasize how helpful the support is to COMOP and that we think it should be expanded through other member national societies of IOF."



Like many osteoporosis societies, South Africa's NOF is in a developmental stage and is currently funded mostly by a number of companies with vested interest in osteoporosis. As the Foundation has grown the need to diversify and spread the administrative workload has become clear. "Given the current changes in our Foundation's organizational structure, fundraising structures and philosophy, focus on specific projects etc, Paul's visit came at an extremely opportune time." Acting as a facilitator rather than prescriptively, Paul helped us to identify the need to change the patients' perception from "victim" to "empowerment", and to broaden both the source

of sponsors and the make-up of the Foundation's Council (currently entirely medical). Educational programmes and possible plans for WOD were also covered. South African members of NOF were enthusiastic about the visit. They emphasized that it had reduced their sense of geographical isolation and suggested that a follow-up visit within a year would be very helpful. Professor S Hough, Chairman of NOF South Africa, said, "Thank you IOF for helping us develop, and for making us feel part of the IOF family!"

One of the strengths of the Targeted Support Program is the trainers' sensitivity to international and cultural variation. A very different member society, the Japan Osteoporosis Foundation, was visited by trainer Karl Wagner. Unlike Western Europe and North America, Japan does not have a non-governmental organisation (NGO) culture and the JOF members feel they need to learn the "NGO trade" and improve their outreach to the public and the medical profession. The Targeted Support program has received a warm welcome by JOF. The Targeted Support visit focused on a few identified priorities, including broadening the income base, hosting a conference to raise awareness of osteoporosis in South-East Asia, and improving communications both with the IOF network and with the public.

Plans are underway to expand Targeted Support in 2000. National societies interested in participating should contact IOF Executive Director Mary Fraser.



PARTNERSHIP WITH BUSINESS AND PROFESSIONAL WOMEN INTERNATIONAL GATHERS MOMENTUM

As we reported in the last edition of IOF News, IOF has formed an exciting new partnership with Business and Professional Women International (BPWI), a global network of professional women working to promote opportunities for women in all parts of the world. The partnership is implemented on a country level, with each member society of IOF deciding for itself on how to further its partnership involvement.

Jordan: In June the Jordanian Osteoporosis Prevention Society (JOPS), which was founded in 1997, was invited by IOF to participate in the regional BPWI symposium. Entitled "Partnerships for the future empowerment of women", the seminar was held at the Grand Hyatt hotel in Ammam and drew participants from all over the world: IOF Executive Director Mary Fraser came from Switzerland and other participants from Palestine, France, Cyprus, Egypt and Lebanon. Mrs Suha Bawwab introduced JOPS to an attentive audience and Dr Sawsan Najmey explained who is at risk of osteoporosis and how it can be prevented. Both Dr Basel Masri, president of JOPS, and Dr Efteem Azar, Vice-President, took part in a final panel discussion where they answered questions about osteoporosis and its management. The event had a concrete result, as the Jordan branch of the BPWI and JOPS agreed to work together to promote knowledge about osteoporosis and its prevention throughout the country.

Taking advantage of the presence of Mary Fraser at the Ammam symposium, an additional press conference featuring osteoporosis was held at the Arab Drugstore, which has donated JD 5,000 (approx US\$ 7,000) towards the rent

and furnishing of JOPS' new offices in Ammam.

Israel: Also in June, a fruitful meeting between Dr Hana Elroy, BPWI President in Israel and Mrs Irit Inbar, Executive Manager of the Israeli Foundation for Osteoporosis and Bone Diseases, led to an agreement between the two organisations to cooperate with each other in activities planned for this year's World Osteoporosis Day (WOD). The collaboration aims to raise the general awareness of osteoporosis among Israeli women, and to lobby the Israeli Ministry of Health to include osteoporosis in the Israeli "Basket of Health".

The two organisations will jointly stage a one-day osteoporosis seminar on WOD. Prominent women from the medical profession, law, Knesset and business will be invited to attend the seminar, which will include talks from osteoporosis experts and a panel discussion of the public health aspects.

Bulgaria: The long-term strategy of the Bulgarian organisation "Women without osteoporosis" (WWO) is to exploit the country's outstanding natural advantages, such as high quality milk products, mineral waters, and a high number of sunny days per year, to encourage foreign investment in health farms for osteoporosis. In June the organisation's Chairwoman Tamara Kovatcheva had a first meeting with Mariana Tzvetkova, President of BPWI-Bulgaria, and Maria Zagorska from the Clubs of Agrarian Women. Here, the representatives were able to agree that WWO and BPWI-Bulgaria will collaborate on common projects. In particular, the regional BPW club in Vratza



Queen Noor, Patron of Business and Professional Women Jordan

will receive information and materials about osteoporosis from local WWO volunteer Dr Ninova, and educational materials and guides to forming support groups will be provided by Ms Tzvetkova to the BPW club in Karlovo.

There is no lack of ideas about other ways that IOF and BPWI clubs can work together at the national level. These range from the straightforward, such as twinning or inviting osteoporosis society representatives to speak at BPWI meetings, to more innovative schemes such as "adopt a project", where national societies would develop discrete, achievable projects for BPWI clubs to sponsor.

IOF NEW WEBSITE GOES LIVE

The new IOF website is now up and running. Although IOF has had a website for some time, the new site offers a vastly extended range of topics with over 250 pages packed with information, from details of IOF committee membership to information on the symptoms and treatment of osteoporosis and links to related sites.

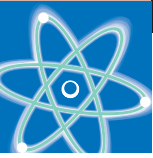
Via the website you can contact the IOF, visit member society's sites, learn about the latest IOF news and upcoming events, read about the role of national osteoporosis societies in fighting the disease, find

advance information about scientific congresses and patient meetings, and much more! Unique to the IOF website are details of grants, research fellowships and meeting sponsorship that IOF provides, and press releases made available by the IOF press centre. A webeditor keeps the website fresh and up-to-date with all the latest news.

The redesign and maintenance of the website has been made possible through generous financial support from: The Alliance for Better Bone Health (Hoechst Marion Roussel and Procter & Gamble), Eli Lilly, Organon, Pfizer and Roche. Our grateful thanks go to them for their support.



Willem de Laat, Medical Director of NV Organon, the Netherlands (left), presenting a cheque for website maintenance to Prof. Pierre D Delmas, IOF President (right) and Mary Fraser, IOF Executive Director (center)



A VIEW FROM CENTRAL AND EASTERN EUROPE

The huge problems of economics and infrastructure faced by the countries of eastern and central Europe are widely recognised. Among other things, the past history of these countries has left a legacy of health problems. A regional consensus meeting held in Budapest in September 1998 highlighted the high prevalence of osteoporosis in central and eastern Europe, comparable in many cases to Scandinavian countries considered European "leaders" in osteoporosis. Epidemiological studies carried out in participation with EFO (now IOF) revealed a country-specific, multifactorial pattern of risk factors. Throughout the region there is a low average calcium intake (approx 600 mg/day for women and 400 mg/day for men) and many people combine a sedentary lifestyle with heavy smoking and drinking. Financial help from a number of pharmaceutical and diagnostic

companies has made possible significant improvements in the diagnosis of osteoporosis: the number of bone densitometers in Hungary has risen from 7 in 1994 to 99, and in Poland from just 2 in 1990 to almost 200 today. Nevertheless, the number of instruments per head is still 4–10 times below European Union countries. Both reimbursement and access to the equipment is limited. Diagnosis by biochemical markers is not widely used, again largely because of inadequate reimbursement.

In terms of treatment, the problem is also a financial one. The most effective drugs on the western European market are available in central and eastern Europe, but the cost is usually prohibitive for average local incomes and may not be covered by the new insurance systems which have replaced generalised social insurance.

Osteoporosis prevention, diagnosis and treatment are coordinated in each country by professional societies, most of which are members of

IOF. Some local experts also serve on the Scientific Advisory Committee of IOF. Nevertheless, most primary care physicians in the region have a limited knowledge of osteoporosis and there are few training opportunities. Given the economic and other difficulties, the amount of research that does go on is to be applauded. Applied research has predominated, but recent basic research has looked into the polymorphism of osteogenesis imperfecta and the involvement of collagen, vitamin D and estrogen receptors in the pathogenesis of metabolic bone disease. A very recent paper published in Osteoporosis International showed Polish and Italian authors collaborating in an investigation of the ultrasound measurement of bone density (Trebacz and Natali, Osteoporosis International 1999; 9: 99-105).

Roman S Lorenc, Professor of Medicine and Biochemistry, Multidisciplinary Osteoporotic Forum, Poland, and member of the IOF Committee of Scientific Advisors.



Organisation

Welcome to new member societies

IOF now represents a total of 96 societies from 57 countries. We warmly welcome the following new member societies. New full members. **Canada:** Osteoporosis Society of Canada. **Columbia:** Asociacion Colombiana de Endocrinologia, Asociacion Colombiana de Osteologia y Metabolismo Mineral. **Croatia:** Croatian League against Rheumatism. **UK:** Osteoporosis 2000. **Uruguay:** Sociedad Uruguaya de Reumatologia. **Venezuela:** Sociedad Venezolana de Menopausia y Osteoporosis. New associate members (start-up national societies may join IOF for up to two years as associate members and receive all member benefits, excluding voting rights, without payment of the annual membership fee). **Palestine:** Palestinian Osteoporosis Prevention Society. **Romania:** Association for Prevention of Osteoporosis in Romania. **Venezuela:** Fundacion Venezolana de Menopausia y Osteoporosis.

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Society*; **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, 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 Osteoporosis Patients' Association*, Hungarian Society for Osteoporosis; **Iceland:** Beinvernd*; **India:** Indian Rheumatism Association; **Ireland:** Irish Osteoporosis Society*; **Israel:** Israeli Foundation for Osteoporosis*, 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:** Lithuanian Endocrine Society, Lithuanian Fund of Osteoporosis*; **Luxembourg:** ALEMO; **Mexico:** Mexican Committee for Osteoporosis Studies (COMOP); **New Zealand:** Australian & New Zealand Bone & Mineral Society; **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, Russian Patient Society of Osteoporosis & Bone Diseases*; **Saudi Arabia:** Saudi Osteoporosis Club; **Slovak Republic:** Slovak Society of Osteoporosis and Metabolic Disease; **Slovenia:** Slovenc 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, Turkish Osteoporosis Society, Turkish Rheumatism Society, Turkish Society of Endocrinology & Metabolism; **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

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Feedback & subscription

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