



International
Osteoporosis
Foundation

Annual Report '98

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It gives me great pleasure to introduce the IOF Annual Report 1998. This first annual report covers a year which saw many significant accomplishments in the fight against osteoporosis. The achievements of IOF and its collaborating partners will be detailed throughout this report. I would like to briefly mention a few highlights:

We played a key role in the June publication and launch of the *Summary Report on Osteoporosis in the European Community – Action for Prevention*, a milestone in recognizing the impact of the disease in Europe. World Osteoporosis Day, celebrated on 24 June, was a fitting occasion to plan national implementation strategies of the report's recommendations. Although it focuses on the European Community, the report is being used as a model in other countries to raise awareness about osteoporosis and the need to allocate greater resources to this growing social health problem.



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Over 4,000 participants from 75 countries worldwide gathered in Berlin for the largest scientific and patient congress on osteoporosis to date. Delegates from the medical, science and health-care fields shared information about the latest research and advances in the disease at the Scientific Conference. The 4th Worldwide Conference of Osteoporosis Patient Societies was held in parallel with a major scientific meeting for the first time, allowing the voice of the osteoporosis patient to be heard clearly.

The most important event of 1998 was undoubtedly the creation of the International Osteoporosis Foundation (IOF) poised to establish wide and powerful networks around the globe. IOF currently has a membership of 74 societies in 46 countries. A restructuring of the Founding Board is in progress and will reflect the Foundation's broad scope and commitment to becoming a truly international organization.

The future composition of the new IOF Board will also emphasize the importance of the osteoporosis patient and their families. Community leaders worldwide with a wide range of non-medical skills and interests are being actively sought to complement the clinical and research competence of the current Board.

IOF, with its tripartite structure representing national osteoporosis societies, scientific excellence and corporate advisory skills, aims to make a major impact on the fight against the disease in 1999 and beyond.

A handwritten signature in black ink, appearing to read 'Pierre D. Delmas'.

Pierre D. Delmas, MD, PhD

On behalf of the Foundation I would like to extend a personal welcome to all the member societies which make up our new global IOF. We must never lose sight of the reason for our existence – to fight osteoporosis, the silent epidemic, using all means at our disposal.

As an umbrella organization IOF exists to support the work of every member society to achieve universal recognition of the disease. Active participation by all of us is crucial to our success in this endeavor.

We have good working tools: the Recommendations of the Report on Osteoporosis in the European Community are sound and comprehensive and can be used as a plan of action worldwide. We enjoy good collaboration with organizations working on related and complementary health issues. But our most important resource is the individuals, committees and working groups of IOF who provide a pool of talent, experience and commitment.

We made excellent progress in 1998. The many events and activities are described throughout this report. We were particularly proud of the support provided to member national societies and their staff through educational grants and the targeted support workshops to improve a multitude of professional skills.

IOF aims to increase its membership in 1999 by intensifying current activities and adding new services, such as an expanded and updated Web site, a News Service for members and the media, more professional skills workshops and increased emphasis on awareness and education programmes about osteoporosis.

I look forward to receiving your comments and suggestions for making IOF a truly great forum for our work against osteoporosis.



Mary Fraser, BSc (Hons) Pharm, Grad. Dip. Mkting



Osteoporosis: Th

■ Osteoporosis is a disease in which the density and quality of bone are reduced, leading to weakness of the skeleton and increased risk of fracture, particularly of the spine, wrist, hip, pelvis and upper arm. Osteoporosis and associated fractures are an important cause of mortality and morbidity.

In many affected people, bone loss is gradual and without symptoms or warning signs until the disease is advanced. Osteoporosis is a global problem which is increasing in significance as the population of the world both grows and ages. For these reasons, osteoporosis is often referred to as the "silent epidemic" (see fig 1).

There are many misconceptions about osteoporosis, for example that it is "an old woman's disease". In fact, bone loss in women can begin as early as age 25. Worldwide, the lifetime risk for a woman to have an osteoporotic fracture is 30-40%. In men the risk is about 13%.

Osteoporosis is a widespread public health problem. More hospital beds are occupied by women over the age of 45 with hip fractures due to osteoporosis than by heart attack or breast cancer patients (see fig 2).

Even so, osteoporosis was not precisely defined as a disease until 1994. The World

Health Organization (WHO) has since identified osteoporosis as a priority health issue along with other major non-communicable diseases.

Who is at risk?

Risk factors for osteoporosis include:

- A maternal history of hip fracture
- Female gender
- Slight body build
- Asian or Caucasian race
- An early menopause
- Primary or secondary amenorrhoea (absence or cessation of menstrual periods)
- Primary or secondary hypogonadism in men (sex hormone deficiency)
- Poor diet, low in calcium
- Lack of exercise
- Smoking
- Regular and excessive alcohol consumption



These photos of Inger Lundegaardh show how osteoporosis transformed the body of a beautiful young woman of 20 into a hunched 57-year old. (Reproduced with permission.)

The Silent Epidemic

Fig 1
50 year forecast for hip fracture incidence in the European Union.

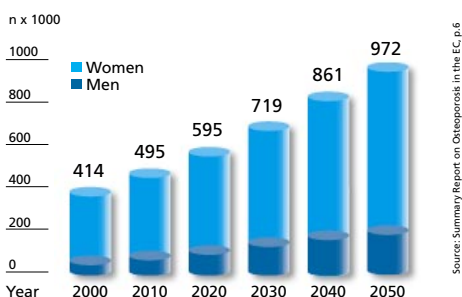
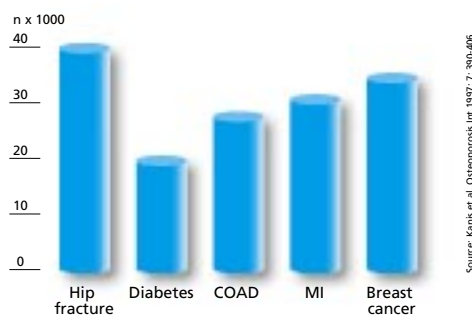


Fig 2
Hospital bed occupancy in women aged 45 years or more. COAD, chronic obstructive airways disease; MI, myocardial infarction.



What can be done?

■ Rapid progress is being made in diagnosis, treatment evaluation and prognosis of osteoporosis. Early detection of bone loss is key to the prevention of suffering and escalation of health care costs. Bone mineral density (BMD) measurements are effective in assessing fracture risk, confirming a diagnosis of osteoporosis and monitoring the effect of treatment. A major concern is that access to measuring equipment and qualified technical personnel – and reimbursement by medical insurance schemes – remain inadequate in a great many countries.

Effective medications are available for prevention and treatment of the disease and

more are being developed. However, all too often health insurance companies do not reimburse the cost of medicines for osteoporosis. In addition, non-medical therapy, such as a healthy diet and exercise, has been shown to have a beneficial effect on bone.

The pivotal role of national osteoporosis societies and support groups cannot be overstated. These offer many invaluable services, from awareness education about the disease to support and advice for sufferers through group sessions and telephone help lines. For this reason, a priority of IOF is to encourage and assist its membership everywhere in developing strong and effective societies.

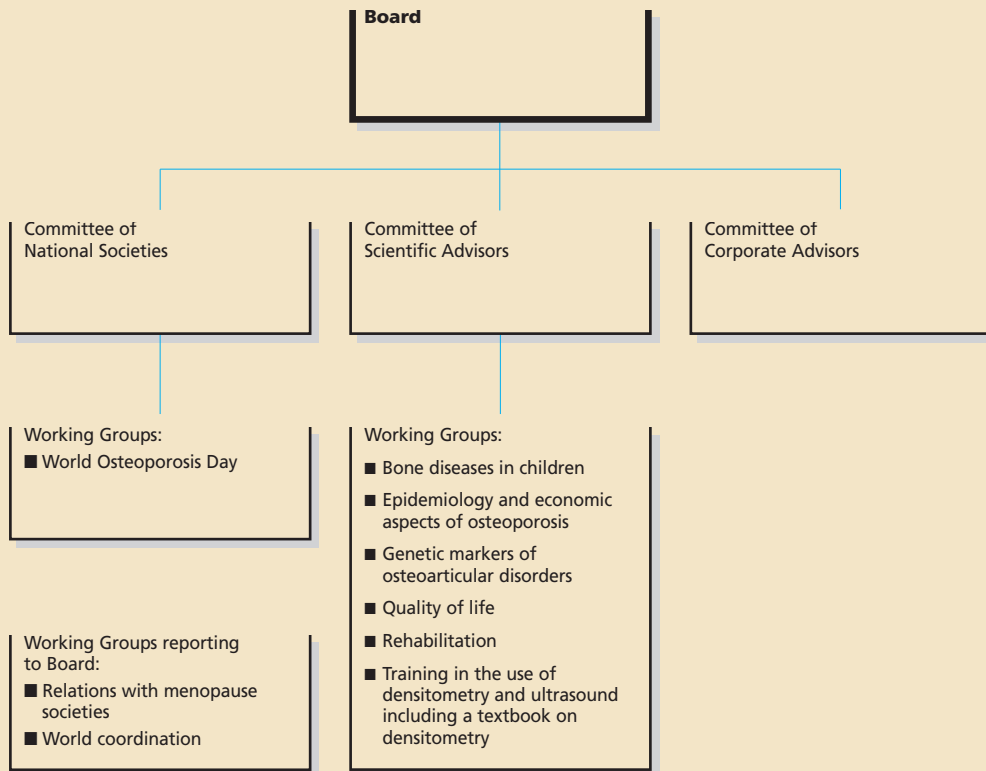


I wish I had the bone scan earlier. (IRL)



The wedding photo of Hans and Ans van den Brink in 1972 show that the happy couple are the same height. Today Hans, 50, is a full head shorter than his wife due to osteoporosis. (Reproduced with permission.)

The Organization



Members of the Founding Board 1998

PROF. MAURICE AUDRAN
PROF. CLAUD 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. LYRITIS
PROF. PIERRE J. MEUNIER
PROF. HELMUT MINNE
PROF. SOCRATES PAPAPOULOS
PROF. JEAN-YVES REGINSTER
PROF. JOHANN D. RINGE

PROF. PETER BURCKHARDT (EX-OFFICIO)
PROF. RENÉ RIZZOLI (EX-OFFICIO)
MR. LEO VAN WERSCH (EX-OFFICIO)

Launch of IOF

■ A new worldwide organization, the International Osteoporosis Foundation (IOF) was created in 1998. The European Foundation for Osteoporosis (EFO), founded in 1987, and the International Federation of Societies on Skeletal Diseases (IFSSD), established in 1995, joined forces to become one organization capable of fighting osteoporosis in every part of the world.

Prof. Pierre D. Delmas, formerly President of EFO, assumed the same position in IOF. The former President of IFSSD, Prof. Carlo Gennari,

assumed the honorary post of Past President alongside Prof. Pierre J. Meunier, Past President of EFO.

“The timing could not be better for the formation of IOF. We have enjoyed a long relationship of collaboration with EFO and IFSSD, and those joint efforts will become, I hope, even stronger now that they are a larger organization with a broader audience and constituency”. Dr. André Prost, WHO Director, Division of Non-communicable Diseases.



Prof. Carlo Gennari and Prof. Pierre D. Delmas.



I've made up my mind never to fall again. (A)

Structure

■ Membership of IOF currently comprises 74 societies in 46 countries. Forty per cent of member societies represent non-European countries, and this geographical diversity will be reflected in a restructured IOF Board. The elected 15-member Founding Board is in the process of reducing its current membership to 10, creating space for new members who will be sought to reflect the global membership of IOF. At the same time the organization aims to broaden the range of competencies represented on the Board by including non-medical members with a wide range of skills

and interests, such as community leaders and individuals experienced in political lobbying, public relations or fundraising.

Chairmen of the three IOF Committees were also elected: Prof. Peter Burckhardt, Committee of National Societies; Prof. René Rizzoli, Committee of Scientific Advisors, and Mr. Leo van Wersch, Committee of Corporate Advisors. They are ex-officio members of the Board.

A World Coordination working group reporting directly to the Board has been formed to strengthen IOF's global scope; Regional Coordinators have been appointed for Asia, Central and South America, and the Middle East.

Committee of Scientific Advisors

■ The Committee of Scientific Advisors (CSA) represents the basis of IOF's scientific integrity and is composed of members from the medical and scientific community. Membership is based on scientific merit. The mandate of CSA is to advise the Board on all scientific matters related to IOF and its objectives to further clinical and basic research.

Research Projects

The Committee organizes many of its activities in research projects or working groups.

Ongoing groups:

- Bone diseases in children
- Epidemiology and economic aspects of osteoporosis
- Genetic markers of osteoarticular disorders
- Quality of life
- Rehabilitation
- Training in the use of densitometry and ultrasound including a text book on densitometry

To reflect IOF's global focus, CSA is in the process of prioritizing its activities for the next several years and is establishing new projects based on need and the interest and expertise of its members.

New proposals include:

- Bone mineral density reference range
- Corticosteroid-induced osteoporosis
- Diagnosis and prevention of vitamin D deficiency
- Guidelines on hormone replacement therapy and selective estrogen receptor modulator use
- Male osteoporosis
- Medical training in bone disorders
- Osteoarthritis
- Osteogenesis imperfecta
- Paget's disease of bone
- Update of clinical guidelines
- Use of biochemical markers of bone remodelling

IOF-CSA welcomes applications to join the Committee from dedicated professionals worldwide interested in the opportunity to participate in multinational research and keep informed about osteoporosis initiatives.



Prof. René Rizzoli, Chairman.



Committee member, Dr. Gyula Poor, Hungary, at work.

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. Mario Passeri, Italy
- Dr. Gyula Poor, Hungary
- Dr. Christine Pouliart, Belgium
- Dr. Jonathan Reeve, UK
- Prof. Jean-Yves Reginster, Belgium
- Prof. Johann D. 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.

Advanced Training Course on Osteoporosis

This annual training course lasting 2.5 days is organized in Lyon, France for up to 180 participants. The course is given by an internationally renowned faculty and has a successful eight-year history. IOF offers 25 grants to healthcare professionals working with member societies who wish to attend the course.

IOF Research Fellowship

In 1998, the first osteoporosis research fellowship was offered. The maximum total amount of the fellowship is Euro 45,000.

The 1998 award was made to Dr. Risto Honkanen, a Finnish epidemiologist who was one of the founders of OSTPRE, the Kuopio Osteoporosis Risk Factor and Prevention Study. With the support of the IOF award, the Research Fellow has been able to analyze data acquired by OSTPRE on individuals threatened by osteoporosis.

Deadline for applications for the 1999 IOF Research Fellowship in osteoporosis and other skeletal diseases is 30 May 1999. Eligibility is restricted to members of IOF's Committees of National Societies and Scientific Advisors.

Dr. Anna Peckham, UK



■ From the age of 15, Anna began to suffer from anorexia. Four years later, as she was finally on her way to putting the eating disorder behind her, she discovered that she had osteoporosis, an "old woman's disease." Now in her late 20s, Anna tells her story hoping

that her experiences may help other sufferers.

At 15 Anna was almost 6 feet tall (180 cm) and weighed 68 kg. She began a diet that was to mark the beginning of her struggle with anorexia. Her periods stopped completely and over the next few years her weight dropped to 37 kg. Treatment, including several months in a child and adolescent psychiatric unit, failed to help.

Finally, at the age of 19, after medical and psychiatric treatment, Anna regained weight and was able to continue her studies and work part-time in a

residential home. It was here that she first noticed back ache but put it down to her work lifting patients. One morning though: "I felt this excruciating pain; I fell to the floor, then crawled along the landing back to bed. It was terrifying because I couldn't stand up."

Anna's general practitioner diagnosed a slipped disc and prescribed bed rest. It was when she started walking again that her mother noticed she was no longer taller than her sisters. She had suffered vertebral fractures and lost 5 cm in height. A bone density scan confirmed osteoporosis.

Anna has been prescribed high-dose contraceptive pills to boost her oestrogen levels, she exercises regularly and has a calcium-rich diet to help increase her bone density.

Anna went to medical school and is now working in the psychiatric unit of North Liverpool University Trust. Because of her personal experience, Dr. Anna Peckham hopes to make a special contribution to this area of expertise.

Mrs. Marie-Lynn Majdalany, Lebanon



■ "It happened to me when I never thought it would, so I would like to help others avoid it."

In my early 40s, I started to suffer from great pain all over my body. Until that time, my daily life had been very active, starting at 5:30 in

the morning and ending late at night.

The pain changed my lifestyle entirely. I became very dependent on other people for walking or driving a car. A physician friend advised me to undergo a bone mineral density test. It revealed that I had osteoporosis. I began a long-term treatment programme

of medication and physiotherapy. In 1997, I underwent a general hysterectomy and was prescribed a hormone therapy.

I became depressed and stopped physiotherapy. I did not want to go out any more since I was walking very slowly. Going up or down stairs was very painful and somehow humiliating.

One day, with the help of my physician, I decided to stop complaining and think positively and began to cooperate actively with the Lebanese Osteoporosis Prevention Society. I have made up my mind to help people avoid or delay this silent disease – and to encourage sufferers like myself to be as positive and active as they possibly can.



The local osteoporosis patient support group helped me a lot. (D)

Mr. Leu Yid Pin, Thailand



■ Leu Yid Pin liked nothing better than his morning walk through his quiet village. Enjoying life as a successful retired businessman, he would stop to chat with his friends before continuing to the sports club for his morning Tai Chi.

His normal routine came to an abrupt end, however, when 84-year old Mr. Leu developed severe back pains. He suffered such pain that he could not even sit down for dinner. He had to ask his wife to help him get dressed. An X-ray taken at the local hospital in Chiang-mai province revealed that Mr. Leu had fractured his fourth lumbar vertebrae, and he was given painkillers.

Two months later he was back in the hospital following another attack of severe back pain. His local doctor took another X-ray and discovered that Mr. Leu had a collapsed spine. By this time he had lost 8 cm of height. It was only when he was referred to a larger hospital in Bangkok that osteoporosis was diagnosed. There he was treated with a bisphosphonate to reduce bone loss.

Mr. Leu's physician, Dr. Suthorn Bavonratanavech notes that "osteoporosis is becoming an increasing problem in this part of the world". Dr. Bavonratanavech's hospital plans to start a special osteoporosis clinic. He also hopes to bring together specialists in orthopedics, obstetrics/gynecology and endocrinology to establish a Thai Osteoporosis Society.

From Concept to Realization: **Report on Osteoporosis in the European Community – Action for Prevention**

■ The Health Promotion and Disease Surveillance unit of the European Commission organized a first meeting with experts on osteoporosis in February 1996. Eight working groups were 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. I would like to express my strong admiration for those committed individuals campaigning for better awareness of osteoporosis.

Dr. Caroline Jackson, Member of the European Parliament

The June launch of the *Summary Report on Osteoporosis in the European Community – Action for Prevention* was a milestone in raising awareness about osteoporosis in Europe and showing the urgent need to allocate greater resources to fight the disease. Publicized and disseminated widely by the European Foundation for Osteoporosis

and Bone Disease – now IOF – the report provides the first collection of extensive data on osteoporosis in the 15 countries of the European Union (EU). The German Green Cross (DGK) and the World Health Organization (WHO) were partners in publicizing this report, which estimates that one in eight EU citizens over 50 will suffer a spinal fracture

“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”,

said Dr. Jackson, whose mother died from complications of osteoporosis.



Dr. André Prost, WHO; Mr. Pdraig Flynn, Member of the European Commission; and Mrs. Mel Read, Member of the European Parliament, enjoy the success of the Launch Meeting.



“Teo” (right), and “Rose” (left) – derived from osTEOpOrose. Teo, a cook who is keen on calcium, and Rose, enthusiastic sportswoman, inform Mrs. Read about healthy bone.



Dr. Caroline Jackson, MEP.



Patients, politicians and scientists unite against osteoporosis.

due to osteoporosis. The report makes important recommendations for action to prevent, diagnose and treat the disease – and serves as a model for government action in all countries.

The well-attended and highly successful launch meeting and press conference at the European Parliament in Brussels heard succinct present-

“For me the most important message that arises from this report is not that osteoporosis is serious, widespread and expensive. We know that. The message I take away is that it can be diagnosed relatively easily, it can be prevented through making informed health decisions, and it can be treated and managed through relatively simple medications and interventions.”

Mr. Padraig Flynn,
Member of the European Commission

ations of the report’s key points by members of the working group. Three osteoporosis sufferers gave their view of the human toll of the disease and expressed the hope that the report would lead to collaboration between governments and professionals in health and education throughout the world.

WOD’98

■ The introduction of the EU Report was planned to coincide with the 3rd World Osteoporosis Day (WOD). The theme for WOD’98 was “Government Action”. The recommendations of the report call for action, and WOD was a unique opportunity for the scientists, healthcare professionals, patients and their families, who make up national osteoporosis societies, to plan collaboration with their politicians and health authorities.

Co-sponsored with WHO, the event provided an all-important focal point to educate the general public and policy makers about prevention and stressed the need for all governments to provide appropriate resources to detect and manage osteoporosis.

Many special activities with excellent media coverage took place in Europe and around the world to mark WOD’98:

■ Lebanon held its National Osteoporosis Week in late June offering free bone mineral density tests, free medications for needy osteoporosis patients and educational programmes about the disease for different audiences, from school children to medical professionals.

■ China gave special media coverage to osteoporosis and disseminated the WOD press pack.

■ South Africa held a series of seminars about the disease across the country.

■ New Zealand opened a “Fit but Fragile” campaign highlighting the importance of healthy bones.

“Early Detection” will be the theme of WOD’99. It will take place on 20 October, a date agreed as being best suited to the majority of participating countries. A special logo for the Day is being created by Lega Italiana Osteoporosi.

“Osteoporosis is a global threat and we are expecting IOF to help us develop guidelines for government action as they have done so successfully in Europe. The disease is a major problem in China and with our ageing population it will become even more of a challenge.”

Prof. Liu Zhonghou, President, Chinese Gerontological Society Osteoporosis Committee

We look forward to the continued support of WHO and to an even more successful and wide-reaching campaign in 1999.



It’s essential to take responsibility. (FIN)

European Congress on Osteoporosis in Berlin, Germany 11-15 September 1998

■ The Berlin congress and associated meetings attracted over 4,000 participants from 75 countries – the largest gathering to date of scientists, medical professionals, health-care industry representatives, staff of osteoporosis societies, patients and government representatives. They came together to learn and discuss all aspects of osteoporosis in a multifaceted forum of events:

- Scientific Congress with satellite symposia by the pharmaceutical industry and a commercial exhibit
- Consensus Conference on Clinical Guidelines for Diagnosis and Treatment of Osteoporosis
- Osteoporosis Patient Societies Conference
- Public Education Day.

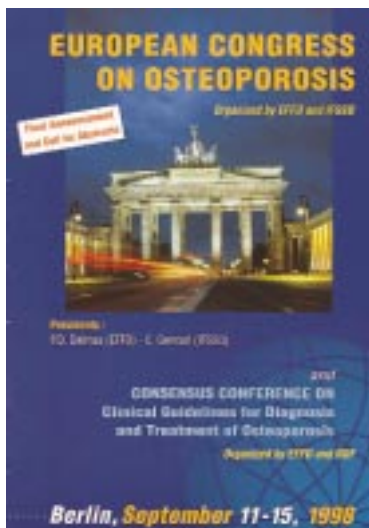
A key event in Berlin was the launch of the new organization, International Osteoporosis Foundation (IOF) uniting EFFO and IFSSD (see story p. 7).

“EFFO was an invaluable resource to national patient organizations. Now, with the Foundation’s larger scope and influence as IOF, we will have access to an even stronger support structure.”

Elizabeth de Boer,
Director of the Dutch Osteoporosis Foundation

“With the creation of IOF, the fight against osteoporosis has become more powerful...Our new partnership will help to mobilize resources and raise awareness about the silent epidemic.”

Prof. Pierre D. Demas, IOF President



A full house at the Osteoporosis Patient Society Conference.

Osteoporosis: A Public Health Problem

■ In his address to the opening session of the Congress, Dr. André Prost, Director of the Non-communicable Diseases Division, WHO, said: Today “we know how to detect osteoporosis, how to treat it and even to some extent how to prevent its most severe effects. But we lack effective social recognition of the vital importance of appropriate prevention and screening strategies, and we lack a common will between patients, healthcare professionals and political leaders. This is why WHO committed itself to support those who are working for the public recognition of



Dr. André Prost, WHO.

osteoporosis as a public health problem. Our commitment is ongoing and we seek continued cooperation with health professionals and patient support groups worldwide. We will participate in updating the consensus on diagnosis and treatment, and in supporting the victims of osteoporosis.”

osteoporosis September



Scientific Congress

■ Presentations covered a wealth of topics. Delegates heard reports that rapid progress is being made in diagnosis, treatment evaluation and prognosis. Major advances include the use of biochemical bone markers and ultrasound techniques to evaluate the impact of new therapies on the disease. Recently developed therapies were described, including raloxifene, a selective estrogen receptor modulator being launched around the world. Studies using the nasal spray salmon calcitonin, or the bisphosphonate agent alendronate alone or in combination with conventional hormone

replacement therapies, appear to have positive effects on bone mass and reduction in fracture rate.

Osteoporosis in men is often underestimated and needs to receive greater attention. Results presented showed that significant bone loss of the hip, forearm and total body can be documented in the majority of men over 50.

Several satellite symposia were presented by industry on new therapies and diagnostic procedures.

The proceedings of the congress are being published in the scientific journal *Osteoporosis International*.



I'm confident that due to the treatment I receive I won't be crippled in the future. (GR)

4th Worldwide Conference of Osteoporosis Patient Societies

■ This parallel meeting of 150 participants from 40 countries was held in connection with the scientific conference for the first time. The objective was to pool the ideas and experiences of the two audiences for a comprehensive perspective of the medical and social aspects of osteoporosis.

Attendees at Berlin were offered a variety of professional skills workshops on topics ranging from fundraising, communications and campaigning to patient services. The workshops were very successful and an expanded programme is being developed for participants

at the 5th World Conference in Toronto, Canada from 5-6 October 1999. The event is being organized by IOF with Osteoporosis Society of Canada.

"The best aspect were the interactive workshops – they helped you to focus and find your own solutions. Next year workshops must be included." (India)

"Best part of the congress." (Finland)

IOF Education Award 1998

■ The first IOF Educational Grant, a total amount of Euro 45,000, was awarded in Berlin. The grant was shared between two national osteoporosis member societies:

■ **Hungarian Osteoporosis Patient Association** for a an educational project for volunteers involved in

Consensus Conference

■ The Consensus Conference on Clinical Guidelines for Diagnosis and Treatment of Osteoporosis was organized jointly with the American National Osteoporosis Foundation. Agreement was reached on paid bone mineral density (BMD) measurements for women over 65 and for those below 65 with risk factors for osteoporosis. It was also agreed that for the treatment of postmenopausal women, evidence-based medicine should be applied to osteoporosis.

the management of osteoporosis self-help groups.

■ **Lega Italiana Osteoporosi** for an awareness campaign to inform pregnant women about the importance of calcium intake during pregnancy.

IOF is accepting applications from member societies for the 1999 Education Award. The deadline is 31 July 1999.



IOF Education Award winners Dr. Istvan Marton (Hungary), Dr. Maria Luisa Bianchi (Italy), Dr. Ada Bossanyi (Hungary).

Targeted Support to National Societies

■ In response to the demand for professional skills training, IOF will in 1999 begin a pilot project of in-depth support to a small number of national societies. Selected member societies will receive training in their country by qualified workshop leaders. The project is being co-ordinated and financed through IOF.

Public Education Day

■ Almost 1,000 people attended this special event during the congress. An appealing mixture of education and entertainment was provided by the hosts, the German Green Cross and the Federation of Osteoporosis Self-help Groups, the umbrella for 230 German self-help groups, and TV personalities. Presentations centred on awareness about maintaining healthy bones through good nutrition and exercise.

Collaboration w

To carry out its mandate to fight osteoporosis, IOF collaborates with organizations and societies having similar objectives and complementary projects.

World Health Organization (WHO)

■ The IOF has enjoyed a long-standing, fruitful working relationship with WHO on issues of importance in osteoporosis.

Osteoporosis was formally identified as a disease by a group of WHO experts in 1994 resulting in publication of *Assessment of Fracture Risk and its Application to Screening for Postmenopausal Osteoporosis* (WHO Technical Report Series 843). IOF provided technical and financial support to the study.

About two-thirds of the WHO group of experts involved in the Report were IOF Board and Committee members.

■ The recent WHO publication *Guidelines for Preclinical Evaluation and Clinical Trials in Osteoporosis* (Geneva, 1998) received technical and financial assistance from IOF.

As a global intergovernmental health organization, WHO has given invaluable support through its involvement in major IOF events and meetings:

■ For the first time, World Osteoporosis Day (WOD) was co-sponsored by WHO and EFO (now IOF).

■ WHO supported the launch of the *Report on Osteoporosis in the European Community – Action for Prevention*, organized the transla-



Dr. Gro Harlem Brundtland, Director-General, WHO.

With Other Organizations

tion of the press packs into Chinese and Russian and disseminated the materials to over 60 regional and national WHO offices.

■ At the International Congress on Osteoporosis in Berlin, Dr. André Prost, Director of WHO's Division of Non-communicable Diseases, announced that osteoporosis must be considered as a priority public health issue. Dr. Prost and his colleague Dr. Nikolai Khaltsev, Team Coordinator, Division of Non-communicable Diseases, also participated in the 4th Worldwide Conference of Osteoporosis Patient Societies and Public Education Day, held in parallel with the Scientific Congress in Berlin (pp. 12-14).

With the new focus by Dr. Gro Harlem Brundtland, WHO Director-

General, on developing a global strategy for prevention and control of non-communicable diseases, IOF looks forward to an even closer collaboration with WHO in the years to come.

In spring 1999, a Round Table article by IOF, "Strong bones in later life: luxury or necessity" will appear in the WHO Bulletin, and a news feature with Dr. Brundtland will be distributed via the IOF News Service to member societies. Mutual participation in events of the two organizations will include IOF involvement in WHO's Active Ageing Initiative and WHO participation in the 5th Worldwide Conference of Osteoporosis Patient Societies and WOD'99.

National Osteoporosis Foundation (USA)

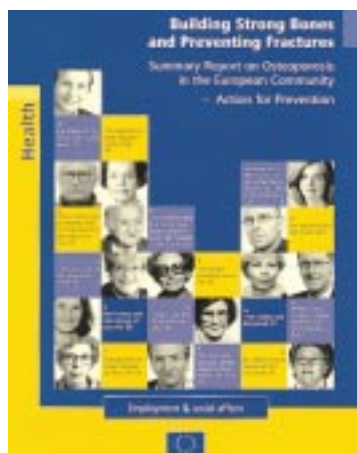
■ Cooperation between the National Osteoporosis Foundation (NOF) and IOF is ongoing and productive as witnessed by the co-produced renowned scientific journal *Osteoporosis International*, now in its ninth year of publication. Collaboration between the two Foundations is set to expand in 1999 with preparations for the jointly-sponsored World Congress on Osteoporosis 2000 which will be held in Chicago, Illinois from 15-18 June 2000. The NOF-IOF organizing committee is planning an outstanding world event. (See also Resources, p. 17.)



Osteoporosis no longer disrupts my daily life. (E)

European Community

■ The collaboration of the European Commission (EC) and IOF began in 1997 with working group meetings of experts on osteoporosis and culminated with the launch of the Summary Report on Osteoporosis in the European Community in June 1998. The EC provided essential financial and practical support for the production, launch and dissemination of materials to promote the recommendations contained in the report and the European Parliament (EP) played a key role in initiating the report. The EP also provided the venue with full translation and chaired the highly successful report launch meeting and press conference.



Because of this strong support – and the dedicated work of people in many countries – the EU Report has had a very high initial impact as measured by media response, references to the report at meetings and in publications and government action at national level. The EC has also supported the electronic

publication of the Summary Report, available in a number of languages via the IOF Web site.

The benefits of the EC-IOF collaboration on this important project will continue to accrue as more and more countries adopt the recommendations as a model for national action to combat osteoporosis.

■ An "ageing population" key action section has been added to the European Union's Fifth Research Framework programme (1998-2002). IOF was actively involved in the consultation process and recommended the inclusion of health problems, including osteoporosis, that arise from an increasingly ageing European population. The Foundation also requested that the EU maintain an ongoing dialogue with non-governmental organizations about this programme.

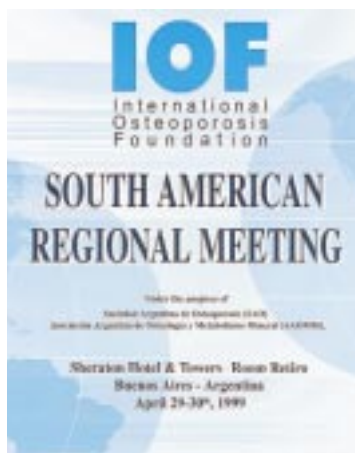
European Advisory Council for Women's Health (EAC)

■ In April 1998 the newly formed EAC drew up an action plan to ensure that mid-life and older women's health is given priority in European health policy. IOF is a member of the Council whose primary goals support and expand on the recommendations of the EU Report. Specifically, the EAC's objectives are: to make women's health a priority for research and health policy; design information



Osteoprevention gym class in Romania.

and health programmes for health-care professionals that address women's health needs; and to re-orient health measures to focus on prevention of disability, independence and quality of life for mid-life and older women.



IOF Sponsorship of Meetings Related to Osteoporosis

■ The Foundation participates in various ways in meetings held by other organizations on issues related to bone health and osteoporosis. Involvement may be through the granting of auspices/endorsement and provision of speakers or funding. To receive IOF endorsement of a meeting, the Board must approve the scientific programme and the event must have more than one commercial funder. 1999 meetings with IOF involvement include:

- "Women's Health after Menopause", Georgetown University Medical Center, Washington, DC, USA.
- IOF South American Regional Meeting, Buenos Aires, Argentina.
- First Mediterranean Conference on "New Strategies in Diagnosis and Treatment of Osteoporosis", Malta.
- Fourth International Conference on "New Actions of Parathyroid Hormone", Malta.

Business and Professional Women International (BPWI)

■ The groundwork for an exciting new collaboration between IOF and BPWI was begun in 1998. Its focus is to bring information about osteoporosis to an influential group of professional and working women for dissemination to a global audience.

Initial plans include information-sharing between IOF national societies and local BPWI affiliates, and joint educational publicity at congresses and other events in 1999, such as at the BPWI World Congress in Vancouver and the 5th Worldwide Conference of Osteoporosis Patient Societies in Toronto organized by IOF and Osteoporosis Society of Canada. BPWI and their local affiliates will support IOF and national societies in the implementation of World Osteoporosis Day activities in 1999.

IOF's New Web Site

www.osteofound.org

■ An extensive and updated Web site has been designed to inform and advise IOF's broad audience of osteoporosis sufferers, member societies, healthcare professionals and scientists, the media, and partners in organizations and corpora-



tions. Information is categorized for easy browsing in main sections such as: Who is IOF; What is osteoporosis; IOF programmes and special projects; IOF press centre, and Osteoporosis advocacy and policy making.

IOF News

■ The Foundation's quarterly newsletter, formerly *EFFO News*, is now in its third year of publication and continues to bring timely information about medical advances in osteoporosis, IOF events and personalities, and news about related organizations and projects. To subscribe to *IOF News*, please refer to the IOF Web site or contact the International Secretariat for details.



Osteoporosis International

■ Editors-in-Chief: Robert Lindsay (USA) and Pierre J. Meunier (France).

This prestigious scientific journal in its ninth year of publication, is produced jointly by the National Osteoporosis Foundation (NOF), USA and IOF. According to the latest journal Citation Reports by the Institute for Scientific Information, the impact factor of *Osteoporosis International* continues to grow and it leads all journals in the Orthopaedics category for the fourth year in a row. The journal, published by Springer Verlag London Ltd., is now appearing monthly. For subscription



information or a free sample issue, please contact Springer Verlag, UK, e-mail: postmaster@svl.co.uk or fax +44 1483 415151. ISSN 0937-941X. Also available online, electronic ISSN 1433-2965. URL <http://link.springer.de>

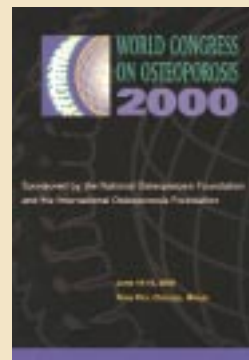
IOF Advanced Training Course on Osteoporosis

■ This 2.5-day course for health professionals is held annually in late January in Lyon, France. 25 grants are available to healthcare professionals working with IOF member societies (see p. 8). For information about the course in 2000, please refer to the IOF Web site or contact the International Secretariat.



World Congress on Osteoporosis 2000

■ Sponsored by NOF (USA) and IOF, this major congress will be held in Chicago, Illinois, from 15-18 June 2000. To receive further information and a registration packet, please contact the Registrar, World Congress on Osteoporosis 2000, fax: +1 202 223 2237, e-mail: wco2000@nof.org



Don't worry and take charge of your life. (B)

Committee of Corporate Advisors

■ The Committee of Corporate Advisors (CCA) is composed of corporations in healthcare and consumer products. Since some of today's most significant osteoporosis research and development work is being undertaken within the corporate arena, this community plays a vital role in our battle to prevent and treat osteoporosis. The Committee of Corporate Advisors gives representation within IOF to this important group.



Mr. Leo van Wersch, Chairman.

Member companies pay a one-time entry fee and yearly dues. Membership entitles a company

to receive *IOF News* and *Osteoporosis International*, the best-selling orthopaedics journal, at a significantly reduced members' rate, and the option to purchase a "hot button" on the IOF Web site (to link their corporate Web site to the Foundation's site).

Members receive early notice of all IOF conferences and courses, are afforded priority placement at events and are made aware of certain sponsorship opportunities available only to members. The Committee meets twice a year. Annual membership dues of the Committee of Corporate Advisors and additional funds raised by the members are put toward the general operation and programme costs of IOF.

Abiogen Pharma srl	Johnson & Johnson Clinical Diagnostics Ltd.	Pierre Fabre Médicaments
Asta Medica	Lunar Europe N.V.	Proctor & Gamble Pharmaceuticals Europe
Beckman-Coulter Hybritech Europe SA	Merck KGaA	Rhone Poulenc Rorer
Besins Iscovesco	Merck Sharp & Dohme	Roche Pharmaceuticals
Boehringer Mannheim (now Roche Pharmaceuticals)	Metra Biosystems	Rotta Research Laboratorium
Byk Gulden Lomberg Chemische Fabrik GmbH	Nestlé Suisse SA	Schering AG
Cassenne	Norland Medical Systems Inc.	SmithKline Beecham
Chiesi	Novartis	Strathmann AG
Cilag International	Novo Nordisk A/S	Sunlight Ultrasound Technologies
Eli Lilly Italia SpA	N.V. Organon	Teva Pharmaceutical Industries Ltd.
Hoechst Marion Roussel Inc.	Osteometer Biotech	Theramex
Hologic Europe NV	Osteometer MediTech A/S	Union Chimique Belge (UCB)
IGEA s.r.l.	Ostex Europe Ltd	Wyeth Lederle
Institut de Recherches Internationales Servier	Pfizer	Yamamouchi Europe BV

List as of 31 December 1998

Funding and Partnerships

Many members and partners contribute funding and services toward the programmes and projects of IOF in addition to their membership fees. Without their generosity, many of our worthwhile projects could never have been carried out.

4th Worldwide Conference of Osteoporosis Patient Societies

Underwriters

- Eli Lilly
- Merck Sharp & Dohme
- Novo Nordisk A/S

Additional funding and services by

- Boehringer Mannheim
(now Roche Pharmaceuticals)
- Bundessebsthilfverband für Osteoporose e.V.
- Deutsches Grünes Kreuz
- Kuratorium Knochengesundheit e.V.
- Pfizer

Satellite Symposia – European Congress on Osteoporosis

- Boehringer Mannheim
(now Roche Pharmaceuticals)
- BYK Gulden & Teva
- Eli Lilly
- IGEA, Hybritech, Osteometer
- Merck KgaA
- Merck Sharp & Dohme
- Novartis
- Proctor & Gamble
- Rhone Poulenc Rorer
- Rotta Research Group
- Schering AG (Press Centre)
- Servier
- Strathmann AG

Osteoporosis Public Education Day

- Bundessebsthilfverband für Osteoporose e.V.
- Deutsches Grünes Kreuz

IOF News

- Boehringer Mannheim
(now Roche Pharmaceuticals)
- Eli Lilly
- Merck Sharp & Dohme
- Springer Verlag London Ltd

World Osteoporosis Day 1998 and Report on Osteoporosis in the European Community

- European Commission
- Eli Lilly
- Merck Sharp & Dohme
- Boehringer Mannheim
(now Roche Pharmaceuticals)
- Novartis
- Merck KgaA
- Osteometer MediTech

World Osteoporosis Day 1998 was co-sponsored by IOF and the World Health Organization



When I think that my mother died of a hip fracture I get really worried. (P)

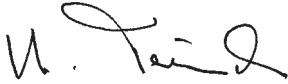
The International Osteoporosis Foundation (IOF) was founded in September 1998 with the merge of European Foundation for Osteoporosis (EFO) and International Federation of Societies on Skeletal Diseases (IFSSD). This merge caused extraordinary growth of the organization and, as a result, 1998 figures cannot logically be compared to prior years' figures for either of the two organizations. The financial statements which follow therefore shows the result of a year filled with great change and, as witnessed by the figures, equally great success.



One of the many goals of the merge was – and still is – to give the new Foundation a steady financial footing on which to exist and fulfill its mission. The first steps in this important process were taken with the IFSSD contribution to the new organization of CHF 118,860. The goal was furthered by the hard-won profit from the European Congress on Osteoporosis of CHF 1,802,026.97 and continued with underwriting funds and donations of CHF 221,655.35. The membership fees of the Committee of Corporate Advisors, CHF 211,787.95, and Committee of National Societies, CHF 21,611.06, also added to the financial security necessary for an organization of this size.

The growth brought about by the merge required that the Foundation expand its programmes to meet the needs of the rapidly-growing constituency. 1998 saw the inauguration of the IOF Member Society Education Grant (an expense of CHF 67,000), the IOF Research Fellowship (CHF 77,265.10), the redesign of the newsletter *IOF News* and the IOF Web site, as well as the decision to increase the publication of our scientific journal *Osteoporosis International* from bimonthly to monthly in 1999. A highlight of the year was the launch of the *Report on Osteoporosis in the European Community – Action for Prevention*, a collaboration of IOF, the Deutsches Grünes Kreuz and the European Commission. Many IOF members participated in the report working group and IOF played a key role in coordinating and publicizing the report. The result was a body of excellent scientific information and recommendations that will have positive lasting significance for healthcare professionals, government officials, the health insurance industry and, most importantly, for osteoporosis patients.

Energized by the achievements of 1998 and bolstered by the financial successes of our programmes, IOF moves forward to 1999 and the turn of the century with renewed vigour for helping the patient and reducing the impact of osteoporosis.


Prof. Herbert Fleisch, Treasurer

Financial Statements

As at 31 December 1998, Expressed in Swiss Francs (CHF)

Income	CHF	Expenses	CHF
<i>Programmes & Projects</i>		<i>Programmes & Projects</i>	
Membership Fees		1998 Advanced Training Course on Osteoporosis including Administration	95,619.83
Committee of Corporate Advisors	211,787.95	Report on Osteoporosis in the EC & 1998 World Osteoporosis Day	538,049.21
Committee of National Societies	21,611.06	4th Worldwide Conference of Osteoporosis Patient Societies including Administration	346,824.37
1998 Advanced Training Course on Osteoporosis	188,089.50	European Congress on Osteoporosis Administration Fees	370,180.35
European Congress on Osteoporosis		IOF Clinical Research Fellowship	77,265.10
Reimbursed Administrative Fees	370,180.35	IOF Member Society Education Grant	67,000.00
Event Income	1,802,026.97	Hungarian Osteoporosis Society Grant	15,427.00
4th Worldwide Conference of Osteoporosis Patient Societies	346,338.70	IOF Web site	7,649.35
Osteoporosis International (Scientific Journal)	120,126.35	Osteoporosis International (Scientific Journal) Editorial Fees & Office Expenses	51,192.40
Report on Osteoporosis in the EC & 1998 World Osteoporosis Day	547,917.05	IOF News (Quarterly Newsletter)	95,180.30
IOF News (Quarterly Newsletter)	75,834.65	Annual Meeting and Member Events	23,981.90
Additional Underwriting & Donations	221,655.35	Printing & Materials	28,528.50
Income from Investments	104,731.00		
Miscellaneous	534.95	<i>Administrative & Operating Expenses</i>	
Total Income	4,010,833.88	Salaries & Office Expenses	58,305.04
		Travel & Representation	75,665.31
		Bookkeeping & Auditing	52,448.60
		Consulting & Legal Fees	53,377.85
		Bank Charges & Extraordinary Expenses for Valuation Risks on Securities	344,262.87
		Membership, Fees & Subscriptions	17,575.65
		Depreciation	20,189.30
		Miscellaneous	7,205.30
		Total Expenses	2,345,928.23

Result of the Year

Assets	CHF	Liabilities	CHF
Bank Accounts & Securities	5,548,242.75	Accounts Payable, Accrued Expenses & Prepaid Income	1,455,088.87
Receivables, Prepaid Expenses & Accrued Income	141,250.60	Short-term Provisions for Planned Projects	282,748.95
Fixed Assets	4.00	Long-term Provisions for General Liability & Valuation Risks on Securities	515,000.00
Total Assets	5,689,497.35	Total Liabilities	2,252,837.82

Donation Capital

Opening Balance	1,652,893.88
Donation Capital International Federation of Societies on Skeletal Diseases	118,860.00
Result of the Year	1,664,905.65
Closing Balance	3,436,659.53
Total Liabilities and Donation Capital	5,689,497.35

1998 financial statement audited by ATAG ERNST & YOUNG

Committee of National Societies (CNS)

ARGENTINA Sociedad Argentina de Osteoporosis, Buenos Aires Dr. Jose Zanchetta Tel. +54 1 822 7230 Fax +54 1 822 7230 **AUSTRIA** Austrian Menopause Society, Vienna Dr. Gerold Holzer Tel. +43 1 40 400 4077 Fax +43 1 40 400 4077 gerold.holzer@akh-wien.ac.at **Austrian Society Bone & Mineral Research, Graz** Prof. Georg Leb Tel. +43 316 385 2383 Fax +43 316 385 3428 ***Österreichische Osteoporose Selbsthilfe (ÖOS), Vienna** Mrs. Mag. Helga Kalmar Tel. +43 1 476 1 5373 Fax +43 1 332 9324 **BELGIUM** Belgian Bone Club, Brussels Prof. Jean-Jacques Body Tel. +32 2 535 3581 Fax +32 2 539 1276 **Société Royale Belge de Rhumatologie, Merksem** Dr. Frank Raeman Tel. +32 3 64 592 00 Fax +32 3 64 429 34 **BRAZIL** Brazilian Society of Osteoporosis, Rio de Janeiro Prof. Rubem Lederman Tel. +55 21 547 0516 Fax +55 21 256 5716 **CHILE** Chilean Society of Osteology and Mineral Metabolism, Santiago Dr. Marianna Arriagada Tel. +56 2 232 1127 Fax +56 2 232 3596 **CHINA** Osteoporosis Committee of China Gerontological Society, Beijing Prof. Liu Zhonghou Tel. +86 10 649 764 20 Fax +86 10 6497 6421 cgsoc@hns.cjth.ac.ca **CUBA** Sociedad Cubana de Reumatologia, Habana Dr. Gil A. Reyes Llereana Tel. +537 215 022 Fax +537 339 086 bcimeq@informe.sld.cu **CZECH REPUBLIC** Czech Society for Metabolic Skeletal Diseases, Prague Dr. Milan Bayer Tel. +420 2 295 271 Fax +420 2 298 675 mbayer@lf1.cuni.cz **DENMARK** Danish Bone Society, Aarhus Tel. +45 89 497 575 Fax. +45 89 497 249 ***Osteoporoseforeningen, Aarhus** Mr. Gunnar Overved Tel. +45 86 139 111 Fax 45 86 136 447 **ESTONIA** Estonian Orthopaedic Society, Tartu Prof. Tiit Haviko Tel. +372 7 448 202 Fax +372 7 448 106 **FINLAND** Finnish Bone Society, Kauniainen Asist. Prof. Christel Lamberg-Allardt Fax +358 9 505 5343 christel.lamberg-allardt@helsinki.fi ***Finnish Osteoporosis Society, Helsinki** Mrs. Maria Valkama Tel. +358 9 612 3670 Fax +358 9 643 193 **FRANCE** ***Association des Femmes contre l'Ostéoporose, Paris** Dr. Marie Aline Limouzin Lamothe Tel. +33 147 630 122 Fax +33 140 549 522 limlam@magic.fr **Groupe de Recherche et d'Information sur les Ostéoporoses (GRIO), Angers** Prof. Maurice Audran Tel. +33 2 41 353 576 Fax +33 2 41 353 700 **GERMANY** Bundesselbsthilfeverband für Osteoporose, Düsseldorf Mrs. Hildegard Kaltenstadler Tel. +49 211 319 165 Fax +49 211 332 202 **Deutsche Gesellschaft für Osteologie, Wiesbaden** Prof. Elmar Keck Tel. +49 611 39 439 Fax +49 611 37 90 76 **Deutsches Grünes Kreuz, Marburg** Mrs. Barbara von Stackelberg Tel. +49 6421 293 128 Fax +49 6421 163 894 Inge.Kokot@Kilian.de **German Academy of the Osteological & Rheumatological Sciences, Bad Pyrmont** Prof. Helmut Minne Tel. +49 5281 151 402 Fax +49 5281 151 402 fuerstenhof.minne@t-online.de **German Society for Endocrinology, Heidelberg** Dr. Reinhardt Ziegler Tel. +49 6221 568 601 Fax +49 6221 565 226 **Kuratorium Knochengesundheit e.V., Budenheim** Dr. Doris Würstl-Lutz Tel. +49 6139 960 474 Fax +49 6139 960 475 DorisWurestl-Lutz@t-online.de **GREECE** Hellenic Society for the Study of Bone Metabolism, Kifissia Prof. Dimitrios Karras Tel. +30 1 623 1541 Fax +30 1 801 8122 **HUNGARY** Hungarian Society for Osteoporosis, Budapest Dr. Istvan S. Marton Tel. +36 1 212 4133 / 269 5590 Fax +36 1 269 5590 / 212 2004 **ICELAND** ***Beinvernd, Laugavegur** Dr. Loafur Olafsson Tel. +35 4 562 7555 Fax +35 4 562 3716 **INDIA** Indian Rheumatism Association, Hyderabad Dr. G. Narsimulu Tel. +91 40 332 0332 Fax +91 40 331 0076 **IRELAND** ***Irish Osteoporosis Society, Dunboyne** Mrs. Mary Crowley Tel. +353 1 825 8159 Fax +353 1 825 8159 crowleym@indigo.ie **ISRAEL** Israel Society on Calcified Tissues & Metabolic Diseases, Petah Tiqva Tel. +972 3 937 6124 Fax. +972 3 937 6143 **ITALY** Italian Society for Mineral Metabolism, Sienna Prof. Ranuccio Nuti Tel. +39 0 557 263 425 Fax +39 0 577 263 446 nuti@unisi.it **Italian Society for Osteoporosis, Padova** Prof. Gaetano Crepaldi Tel. +39 0 498 212150 or 52 Fax +39 0 498 2121 51 **Italian Society of Rheumatology, Verona** Prof. Silvano Adami Tel. +39 0 45 633 8607 Fax +39 0 45 795 0188 adami@borgoroma.univr.it **Lega Italiana Osteoporosi, Milan** Prof. Maria Luisa Bianchi Tel. +39 0 258 211 483 Fax +39 0 239 211 533 ml.bianchi@auxologico.inet.it **JAPAN** Japan Osteoporosis Foundation, Tokyo Prof. Hirotohi Morii Tel. +81 3 5640 1841 Fax +81 6 6645 3808 **Japanese Society for Bone and Mineral Research, Shiga** Prof. Tatsuo Suda Fax +81 3 3784 5555 **JORDAN** Jordanian Osteoporosis Prevention Society (JOPS), Amman Dr. Basel Masri Tel. +962 6 568 1693 Fax +962 6 562 3955 bmasri@nets.com.jo **KOREA, SOUTH** Korean Society of Osteoporosis



Prof. Peter Burckhardt, Chairman.

*Associate Member

CNS currently comprises
74 full or associate member societies
in 46 countries.

To apply for IOF membership,
please see inside back cover.

Research, Seoul Dr. Seung-Kil Lim Tel. +82 2 361 5432 Fax +82 2 393 6884 esk@yung.yonsei.ac.kr **LEBANON** Lebanese Osteoporosis Prevention Society (LOPS), Beirut Dr. Ghassan Maalouf Tel. +961 1 44 2166 Fax +961 1 58 3599 ttsamim@inco-com.lb / GNN@BIGNET.COM.LB **Soci t  Libanaise de Rhumatologie, Beirut** Dr. Said Attaoui Tel. +961 1 204 165 Fax +961 1 648 315 SORISALB@CYBERIA.NET.LB **LITHUANIA** Lithuanian Endocrine Society, Kaunas Prof. Liudvikas Lashas Tel. +370 7 797 888 Fax +370 7 730 847 *Lithuanian Fund of Osteoporosis, Vilnius Dr. Vidmantas Alekna Tel. +370 2 624 437 Fax +370 2 624 437 alekna@ktl.mii.lt **LUXEMBOURG** Association Luxembourgeoise d'Etude du M tabolisme Osseux et de l'Ost oporse (ALEMO), Esch sur Alzette Dr. Camille Kemmer Tel. +352 540 596 Fax +352 540 430 **NETHERLANDS, THE** Dutch Society for Calcium & Bone Metabolism, Rotterdam Dr. H.A.P. Pols Fax +31 10 463 3268 POLS@EPIB.fgg.eur.nl **Osteoporose Stichting, Rosmalen** Dr. J.C. Netelenbos Tel. +31 20 444 0530 / 444 0537 Fax +31 20 444 0502 c.netelen@azvu.nl **Osteoporose Vereniging, Rosmalen** Mrs. Elizabeth de Boer Oosterhuis Tel. +31 735 21 94 45 Fax +31 346 266 479 osteoporose@wxs.nl **NORWAY** Norsk Osteoporoseforening, Oslo Mrs. Wenche Gaaserud Tel. +47 224 49 480 Fax +47 224 47 621 **Norwegian Society for Rheumatology, Oslo** Prof. Forre Oystein Tel. +47 228 67 010 Fax +47 229 43 872 **PHILIPPINES** Osteoporosis Society of the Philippines, Manila Prof. Tito Torralba Tel. +632 731 3001 ext.288 Fax +632 731 3050 **POLAND** Polish Foundation of Osteoporosis, Bialystok Prof. Janusz E. Badurski Tel. +48 85 7420 134 Fax +48 85 7420 134 / 7445 440 **Multidisciplinary Osteoporotic Forum, Cracow** Prof. Edward Czerwinski Tel. +48 12 188 821 Fax +48 12 188 227 **PORTUGAL** Associa o Nacional contra a Osteoporose (APOROS), Lisbon Dr. Viviana Tavares Tel. +351 1 294 0294 Fax +351 1 778 6543 Associa o Portuguesa de Osteoporose (APO), Porto Dr. Domingos Araujo Tel. +351 2 617 7870 Fax +351 2 617 7870 **Sociedade Portuguesa das Doenas Osseas Metab licas (SPODOM), Lisbon** Dr. Jaime C. Branco Tel. +351 1 365 0000 Fax +351 1 365 0198 **ROMANIA** Romanian Society of Osteoporosis, Bucharest Dr. Daniel Gregorie Tel. +401 230 3632 Fax +401 230 3632 **Romanian Society of Rheumatology, Bucharest** Dr. Catalin Codreanu Tel. +40 13 11 1880 Fax +40 13 11 1880 **RUSSIA** Russian Association on Osteoporosis, Moscow Dr. Lydia Benevolenskaya Tel. +7 095 114 4478 Fax +7 095 114 4281 **SAUDI ARABIA** Saudi Osteoporosis Club, Riyadh Dr. Mahmoud El-Desouki Tel. +966 1 467 2436 Fax +966 1 467 2393 nuclear@ksu.edu.sa **SLOVAK REPUBLIC** Slovak Society for Osteoporosis & Metabolic Disease, Piestany Prof. Pavol Masaryk Tel. +421 838 762 3511 Fax +421 838 772 1192 masaryk@vurch.sk **SLOVENIA** Slovene Bone Society, Ljubljana Mr. Andreja Kocijancic Tel. +386 61 1322 270 Fax +386 61 1321 178 Andreja.Kocijancic@kcij.si **SOUTH AFRICA** National Osteoporosis Foundation, Cape Town Mrs. Michele Wolman Tel. +27 21 931 7894 Fax +27 21 931 7075 nofsa@iafrica.com **SPAIN** Fundaci n Hispana de Osteoporosis y Enfermedades Metab licas Osseas (FHOEMO), Madrid Prof. Aurelio Rapado Tel. +34 91 578 3510 Fax +34 91 578 3510 fhoemo@mail.todoesp.es **Sociedad Espa ola de Investigaci n Osea y Metabolismo Mineral (SEIOMM), Las Palmas de Gran Canaria** Dr. Manuel Sosa Henriquez Tel. +34 928 45 1427 Fax +34 928 45 1428 msosa@cicei.ulpgc.es **SWEDEN** Riksf oreningen Osteoporotiker (ROP), G teborg Mrs. Sonja Rembo Tel. +46 31 169 484 Fax +46 31 778 1064 rembo@telia.com **Swedish Osteoporosis Society, G teborg** Prof. Dan Mellstr m Tel. +46 31 61 7722 Fax +46 31 16 3167 **SWITZERLAND** Association Suisse Contre l'Ost oporse, Lausanne Prof. Peter Burckhardt Tel. +41 21 314 0870 Fax +41 21 314 0871 Peter.Burckhardt@chuv.hospvd.ch *Donna Mobile, Sissach Mrs. Monique Ehinger Krehl Tel. +41 61 973 1010 Fax +41 61 973 1011 **THAILAND** Thai Orthopaedic Association, Bangkok Tel. +66 1 4197 526 Fax. +66 1 2720 993 **TURKEY** Rheumatism Society, Istanbul Dr. G zin Dilsen Tel. +90 212 265 22 97 Fax +90 212 270 74 19 **UNITED KINGDOM** Bone & Tooth Society, Sheffield Prof. Richard Eastell Tel. +44 114 271 4705 Fax +44 114 261 8775 r.eastell@sheffield.ac.uk **National Osteoporosis Society, Bath** Mrs. Linda Edwards Tel. +44 1761 471 771 Fax +44 1761 471 104 l.edwards@nos.org.uk **UKRAINE** Ukraine Association on Osteoporosis, Kiev Dr. Vladislav Povoroznjuk Tel. +380 44 430 4174 Fax +380 44 432 9956 vlad@POVOROZNUK.Kiev.UA **USA** International Society for Clinical Densitometry, Washington, DC Mr. Timothy W. Gordon Tel. +1 202 828 6056 Fax +1 202 857 1102 tim_gordon@dc.sba.com **YUGOSLAVIA** Yugoslav Osteoporosis Society, Nis Dr. Aleksandar Dimic Tel. +381 18 444 43 Fax +381 18 444 43 / 542 084 adimic@kalca.junis.ni.ac.yu

Membership of International Osteoporosis Foundation

■ To fulfill its mandate to fight osteoporosis, IOF actively seeks to broaden its global network. Societies, scientists and corporations working in areas related to the disease are warmly encouraged to apply for membership of the committee appropriate to their professional function.

For information about the **Committee of Scientific Advisors**, see p. 8; details about the **Committee of Corporate Advisors** are found on p. 18.

Committee of National Societies (CNS)

■ The benefits of CNS membership include:

- Information on international osteoporosis initiatives by IOF, including lobbying for recognition of the disease at international organization and government levels.
- International visibility through IOF communication channels: *IOF News*, press releases, scientific documents and an extensive Web site; discounted subscription rate to the scientific journal *Osteoporosis International*.
- Participation in international events such as World Osteoporosis Day; travel grants to attend IOF meetings.
- IOF support through educational grants (see p. 13-14), grants to attend the annual Advanced Training Course on Osteoporosis (p. 17), and professional skills training.
- Each year IOF offers financial support of \$10,000 to a national society member to hold a training

course or conference in their country. CNS members themselves decide who should receive funding.

In 1998, Hungary received this support to hold the First Central and Eastern European Osteoporosis Meeting in Budapest. An objective was to present data collected in the region supporting and expanding on the EU Report (p. 10).

- Newly formed national societies with limited resources are encouraged to join CNS as Associate Members enjoying all the benefits of full membership, except for the right to vote at committee meetings.

No membership fee is charged for the first two years.

Membership application forms are available from the **International Secretariat** or on the **IOF Web site**.