A thematic report, written on behalf of the IOF Committee of Scientific Advisors by Juliet Compston, Professor of Bone Medicine, University of Cambridge School of Clinical Medicine, Cambridge, UK. Professor Compston is a member of the Board of the International Osteoporosis Foundation and Chairman of the European Union Osteoporosis Consultation Panel.

Invest in your bones
Stand Tall, Speak Out
Take action to promote osteoporosis policy change
International Osteoporosis Foundation (IOF)

IOF is an international non-governmental organization, which is a global alliance of patient, medical and research societies, scientists, healthcare professionals and the health industry. IOF works in partnership with its members and other organizations around the world to increase awareness and improve prevention, early diagnosis and treatment of osteoporosis.

Although osteoporosis affects millions of people all over the world, awareness of the disease is still low, doctors often fail to diagnose it, diagnostic equipment is often scarce, or not used to its full potential, and treatment is not always accessible to those who need it to prevent the first fracture. IOF’s growing membership has more than doubled since 1999, reflecting the increasing international concern about this serious health problem. There are 186 member societies in 90 locations worldwide (June 2008). IOF member societies represent 5.33 billion people, which is equivalent to 82% of the world’s population.

For more information about IOF and to contact an IOF member society in your country please visit: www.iofbonehealth.org

IOF
Rue Juste-Olivier 9
CH-1260 Nyon
Switzerland
Tel: +41 22 994 0100
info@iofbonehealth.org
www.iofbonehealth.org

What is Osteoporosis?

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 women over 45, osteoporosis accounts for more days spent in hospital than many other diseases, including diabetes, myocardial infarction and breast cancer.
- It is estimated that only one out of three vertebral fractures come to clinical attention.


Normal Bone  Osteoporotic Bone
This year’s Thematic Report focuses on the continuing need to demand osteoporosis policy change. It is a “call to action” to ensure that we build upon the advances that have already been made and that we do not lose sight of the realities that touch millions of people every day. The reality is that between twelve to twenty percent of people die within one year following a hip fracture, that only one in two osteoporotic vertebral fractures is diagnosed by a physician, and that many health insurance schemes will not cover diagnosis and treatment prior to the first fracture.

In an ideal world, all children would achieve optimal bone mass during their growth and they would maintain this lifelong through good nutrition, exercise and a healthy lifestyle. Accurate and rapid diagnosis of osteoporosis would be accessible to all, and people at risk of osteoporosis would be encouraged to take preventative measures. Osteoporosis would be known for what it is – a serious, worldwide health threat that manifests itself in older age.

While we are still far from seeing a world without osteoporotic fractures, the osteoporosis movement has come a long way since 1994, when the World Health Organization officially acknowledged osteoporosis as a disease and established a standard practical definition. The fight against osteoporosis has become a large global social movement, with corresponding advances in the fields of science, healthcare, public awareness, and policy change. Strong national osteoporosis societies skilled in patient support, lobbying and public awareness have considerably raised the profile of the disease in recent years.

This report presents recent socioeconomic data and advances in the prediction of fracture risk as well as examples of where successful campaigns have achieved significant changes in healthcare policy.

Osteoporosis must be prioritized and sufficiently recognized in health and social care policy around the world. Each country or region needs to develop and implement its own strategy to address the silent epidemic. It is time to stand tall, to speak out for bone health.

Juliet Compston, FMedSci, Professor of Bone Medicine,
University of Cambridge School of Clinical Medicine, Cambridge, UK
Much can be done to reduce the chances of getting osteoporosis. First, there are a number of lifestyle changes that can improve bone health, for example taking regular exercise and having a balanced diet with sufficient calcium and vitamin D. *Bone Appetít*, the 2006 IOF thematic report on osteoporosis and the IOF website provide valuable dietary information. Avoiding cigarette smoking and excessive alcohol intake also has benefits for the skeleton.

Since nearly all fractures follow a fall, actions to reduce the risk of falling are important, particularly in older people, and may often be achieved by simple measures such as improving lighting, correcting poor eyesight and removing hazards such as uneven paving stones and loose wires. The IOF report, *Beat the Break – Know and Reduce Your Osteoporosis Risk Factors*, outlines the major risk factors for osteoporosis and what steps can be taken to reduce them (see IOF website). Furthermore, the risk of fracture can now be accurately assessed, so that people in need of treatment can be identified, and finally, a number of cost-effective treatments are now available. However, audits in many parts of the world have shown that diagnosis and treatment of osteoporosis is often neglected, even amongst people who have had a fragility or low trauma fracture. This reflects the failure of many national governments to treat osteoporosis as a major health priority and to provide adequate resources for its detection and treatment.

The IOF and its members strive to attain better access to diagnosis and treatment for the millions of people with osteoporosis around the world. The most direct way to influence health policy – and ultimately get a better deal for people with osteoporosis – is to educate the health policy decision makers about osteoporosis and its burden on society.

Osteoporosis is a disease in which the bones become fragile and break easily. The resulting fractures occur most frequently in the hip, spine and wrist and, around the world, affect one woman in three and one man in five over the age of 50. These fractures are a major cause of suffering, disability and death in the older population and their costs to healthcare services exceed those of many other chronic diseases, for example heart disease, stroke and breast cancer. Furthermore, because of the increasing number of elderly people in the population, the number of fractures due to osteoporosis is set to increase two- to three-fold over the next few decades. This imminent increase in the number of people affected poses a major challenge to healthcare systems throughout the world.

This imminent increase in the number of people affected by osteoporosis poses a major challenge to healthcare systems throughout the world.

The reason that the skeleton often becomes fragile in later life is that ageing brings an imbalance in the normal turnover of bone. Bone is a living tissue that is constantly being renewed in order to maintain its strength. This process involves the removal of old bone followed by formation of new bone. In childhood and adolescence, more bone is formed than removed, but as people age this balance shifts so that the amount of bone formed cannot keep up with the amount being removed. This imbalance leads to bone loss and weakens the bone structure so that fracture is more likely to occur.

Many national governments have failed to treat osteoporosis as a major health priority and to provide adequate resources for its detection and treatment.

IOF and its members strive to attain better access to diagnosis and treatment for the millions of people with osteoporosis around the world. The most direct way to influence health policy – and ultimately get a better deal for people with osteoporosis – is to educate the health policy decision makers about osteoporosis and its burden on society.
Osteoporosis – Socioeconomic Reality

Incidence

Osteoporosis is a major global health problem that is likely to become even more serious as people live longer. Around the world, one in three women and one in five men over the age of 50 will experience an osteoporotic fracture in their lifetime\(^1\). Data show that nine million osteoporotic fractures occurred worldwide in 2000. Europe and the Americas accounted for just over half of all these fractures while most of the remainder occurred in the Western Pacific region and in Southeast Asia\(^3\). About 1.6 million of the 9 million fractures occurring globally were of the hip. Hip fractures are a major cause of disability and loss of independence. In addition, in the first year following a hip fracture mortality rates are as high as 20%\(^4\). Despite this worrying statistic, 80% of those who are at high risk of osteoporosis, and have suffered at least one fracture, have neither been identified nor treated for the disease\(^5\).

Socioeconomic cost

Osteoporosis takes a huge personal and economic toll. The personal toll can be measured in the degree and duration of disability, described by scientists as “Disability-Adjusted Life Years” or DALYs. In Europe, the disability due to osteoporosis is greater than that caused by cancers with the exception of lung cancer (see Fig. 1b), and is comparable or greater than that lost to a variety of chronic non-communicable diseases such as rheumatoid arthritis, asthma, and high blood pressure-related heart disease (see Fig. 1a).

The economic cost of osteoporosis is staggering. In 2000, the number of osteoporotic fractures in Europe was estimated at 3.79 million of which almost 24% were hip fractures. The total direct costs were estimated at €31.7 billion (€1 = US$1.55) and are expected to increase to €76.7 billion in 2050 based on the predicted changes in European demography\(^6\).

In Australia, estimated annual costs for treating fractures in those 60 years and older is about AUD 780 million (circa US$740 million)\(^7\). Estimates in New Zealand suggest first-year costs for hospitalization, recovery, and residential care were the equivalent of US$25,100 (inflation adjusted) and for the second year US$15,000\(^8\). The IOF report, “Osteoporosis in the Workplace” published in 2002 on the occasion of World Osteoporosis Day, estimated the direct cost of treating workplace-related osteoporotic fractures in just the U.S., Canada, and Europe as US$ 48 billion per year.

Comparisons of lost years of healthy life due to osteoporosis and other disease

<table>
<thead>
<tr>
<th>Disease</th>
<th>DALY’s (000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Osteoporosis</td>
<td>3453</td>
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<tr>
<td>IHD</td>
<td>1726</td>
</tr>
<tr>
<td>COPD</td>
<td>1359</td>
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<tr>
<td>OA</td>
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<td>Alzheimer’s</td>
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<td>Cirrhosis</td>
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<td>Asthma</td>
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<td>Migraine</td>
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<td>Hypertensive HD</td>
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<tr>
<td>RA</td>
<td>73</td>
</tr>
<tr>
<td>Peptic ulcer</td>
<td>2936</td>
</tr>
<tr>
<td>Parkinson’s</td>
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<tr>
<td>Multiple sclerosis</td>
<td>269</td>
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<tr>
<td>BPH</td>
<td>307</td>
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DALY – Disability adjusted life years

<table>
<thead>
<tr>
<th>Disease</th>
<th>DALY’s (000)</th>
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</thead>
<tbody>
<tr>
<td>Osteoporosis</td>
<td>2006</td>
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<tr>
<td>Lung</td>
<td>3244</td>
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<tr>
<td>Colorectum</td>
<td>1862</td>
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<tr>
<td>Breast</td>
<td>1703</td>
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<tr>
<td>Stomach</td>
<td>1352</td>
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<tr>
<td>Lymphoma/Myeloma</td>
<td>733</td>
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<tr>
<td>Leukaemia</td>
<td>712</td>
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<tr>
<td>Pancreas</td>
<td>705</td>
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<tr>
<td>Oropharynx</td>
<td>582</td>
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<tr>
<td>Prostate</td>
<td>541</td>
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<tr>
<td>Liver</td>
<td>532</td>
</tr>
<tr>
<td>Ovary</td>
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<tr>
<td>Uterus</td>
<td>454</td>
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<tr>
<td>Bladder</td>
<td>438</td>
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<tr>
<td>Oesophagus</td>
<td>428</td>
</tr>
<tr>
<td>Cervix</td>
<td>392</td>
</tr>
<tr>
<td>Skin</td>
<td>266</td>
</tr>
</tbody>
</table>

Adapted from Johnell O, Kanis JA. An estimate of the worldwide prevalence and disability associated with osteoporotic fractures. Osteoporos Int 2006, 17(12):1726-1733
On top of these statistics, many experts believe that fracture rates are being significantly underestimated, since those who suffer fractures are often not being diagnosed with osteoporosis. For example, a multicenter, multinational study of nearly 2,500 osteoporotic women showed that vertebral fractures, present in ~30% of the women at baseline, were markedly under-diagnosed in radiology reports. The under-diagnosis was apparent in all geographical regions. The proportion of vertebral fractures that goes unrecognized is as high as 46% in Latin America, 45% in North America, and 29% in Europe, South Africa, and Australia. The failure to detect vertebral fractures is likely due to a combination of technical issues related to the X-rays, and failure to provide adequate education about osteoporosis to radiologists. Whatever the cause, under-diagnosis of vertebral fracture is a worldwide problem.

There are also substantial indirect and hidden costs incurred in treating osteoporotic fractures. Lost productivity (indirect costs) in the workplace due to osteoporotic fractures, and to time-off to care for family members who are disabled due to fracture, affects both employers and employees. Many of these costs are difficult to establish, but the “Osteoporosis in the Workplace” report estimated that in the United States alone, indirect costs due to osteoporosis-related disability and death could amount to between US$ 4.5 billion and US$ 6.4 billion annually.

80% of those who are at high risk of osteoporosis, and have suffered at least one fracture, have neither been identified nor treated for the disease.

![Fig. 2: Projected burden of osteoporotic hip fractures worldwide](image)

**Estimated No of hip fractures (1000s)**

- **1990**
- **2050**

**Total No of hip fractures:**

- **1990 = 1.66 million**
- **2050 = 6.26 million**

Adapted from Cooper C., Melton U., Osteoporosis Int. 2:285-289, 1992

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**Projections**

The incidence of fractures is predicted to grow as the world’s population ages. In Europe, for example, the number of men and women over age 65 will increase by 240% and 160%, respectively, by 2050. As older people are at particularly high risk of osteoporotic fractures, projections for the number of fractures and associated costs are cause for concern. In the 40 years to 2050, hip fracture incidence in North America and Europe will double, in Asia it will increase around fivefold, and in Latin America it could increase by as much as sevenfold (see Fig. 2). Scientists predict that among U.S. women over 45 years old, there will be 5.2 million new osteoporotic fractures during the 10 years 2005-2015. This translates into a healthcare expenditure of about US$ 45 billion.

In its recent publication “America’s Bone Health: The State of Osteoporosis and Low Bone Mass”, based on year 2000 census data, the U.S. National Osteoporosis Foundation publishes prevalence estimates and projections for low bone mass, a major indicator of osteoporosis and fracture risk. The report estimates that in the United States the number of people aged 50 and over with osteoporosis may rise to almost 12 million individuals by 2010 and to approximately 14 million by 2020 if additional efforts are not made to prevent the disease.

Worldwide, the cost of treating just osteoporotic hip fractures in 2050 is estimated to be in the range of US$ 132 billion.
A Bulgarian perspective – A fractured hip costs at least US$ 11,960

Maria, 75-years old, lives alone on the 11th floor of a city apartment building. Her history of osteoporotic fractures began in 2003 when she broke her wrist. At the beginning of 2006 an X-ray of her spine showed fractured vertebrae and at the end of November 2006 she fractured her right hip.

“I was waiting for a bus at the stop near the school, when a big cheerful dog jumped up at me. Such a reaction was unexpected and I staggered and fell, but I could not get up again. Each time I tried to take a step, but couldn’t due to the excruciating pain in my pelvis. So I stayed at the bus stop about 3 hours – I felt awkward about asking passers-by for help. Then a neighbour saw me and, understanding what had happened, she went home and called the emergency services.”

Maria was taken to hospital immediately and operated on. When discharged, she remained immobile for another month. Her neighbours and volunteers from the Association “Women without Osteoporosis” helped her – they took turns cooking and bringing food, others helped her to the toilet, while others helped by cleaning and buying her medication.

“After the first month, when I went for a follow-up examination, they ascertained that my bone had healed badly and my leg was about 3 cm shorter. I was taken to the hospital again and operated on a second time.”

Maria paid more than Bulgarian Lev 2,800 BGN (circa US$ 2,210) simply for her treatment in hospital and she continues to pay additionally for assistance and for physiotherapy. She estimates that the state has paid approximately BGN 8,000 for her 52-day stay in hospital. In addition, every month she pays BGN 34 for medication to prevent blood clots and for aspirin, as well as a significant amount for medication to treat high blood pressure.

“So, how could I afford about BGN 70 more for osteoporosis medication and BGN 10 more for calcium with vitamin D? Two years ago, the Health-Insurance Fund reimbursed it, so that we only paid a small additional amount. I used to take my osteoporosis medication regularly then, but I had to stop when the reimbursement was cut back. In the two months following my fracture, BGN 10,000 had been spent…”

Maria is, quite frankly, puzzled. Having worked in the construction business all her life, she is used to the idea of cost-effectiveness. Maria finds it quite illogical to save on prevention and treatment only to have to pay huge sums for fracture repair and rehabilitation.

“I have written down almost all the expenses – my expenses, as well those of the state. It turns out that if the Health-Insurance Fund had covered the cost of osteoporosis medication two years ago, when it was prescribed, it would have cost an average of around BGN 1,000 (circa US$ 800) yearly. At present, only from November till June, more than BGN 15,000 (circa US$ 11,960) has been spent as a result of my hip fracture.”

This is not economically effective and is counterproductive in terms of disease prevention and health protection.

Translated and summarized from an original article by author Aida Panikian, which appeared in the newspapers “Osteoporosis” and “We are healthy”, Photo by Aida Panikian
Osteoporosis – Healthcare Realities

Important care gaps still need to be addressed
The cost-effectiveness of treatment in individuals at high risk of fracture is well established. However, reimbursement for diagnosis and treatment are lacking or restricted in many countries, limiting access to appropriate diagnostic facilities and therapies. This situation is partly due to misconceptions shared by politicians, healthcare providers, and those with osteoporosis, alike. Osteoporosis is too often perceived as being less urgent, less burdensome, and not as serious as more high profile diseases such as cancer and heart disease.

However, the facts paint a very different picture. A recent study of over half a million post-menopausal women aged 50-64 years in the U.S. shows that the average annual direct cost to employers for treating osteoporosis (US$ 7.65 million) is comparable to that spent on breast cancer (US$ 5.89 million) and cardiovascular disease (US$ 15.56 million)\(^1\). In Sweden, inpatient hospital costs due to osteoporotic fractures are higher than those incurred due to breast and prostate cancers, or heart attacks (myocardial infarction), and only marginally lower than stroke\(^2\) (see Fig. 4).

By failing to provide adequate funds for prevention and diagnosis, healthcare systems worldwide are missing out on an opportunity for savings. According to one model of healthcare costs, US$ 48,600 is saved when a 62-year-old woman with osteoporosis is treated for 5 years with a drug that cuts hip fracture rates in half\(^3\).

Measuring cost-effectiveness
The cost-effectiveness of treatment depends partly on economic factors within individual countries, particularly the gross domestic product (GDP) and the percentage spent on health. A recent report from the World Health Organization Scientific Group on assessment of osteoporosis at the primary healthcare level suggests that treatment is eminently cost-effective for many people with osteoporosis in many countries.

Cost effectiveness is usually assessed by how much money has to be spent to save one quality-adjusted life year (QALY). A QALY is a measure of an individual’s state of health (for example, one QALY equals either one year of good health or two years of half-perfect health). In the U.K., according to the guidelines established by the National Institute for Health and Clinical Excellence (NICE) a figure of £30,000 per QALY, or less, is considered cost-effective. According to the WHO Scientific Group technical report, intervention for many patients is cost-effective according to that criterion, including women over the age of 50 years who had a prior fracture and have osteoporosis, and those over 60 years who have osteoporosis even if they have not had a prior fracture (see Fig. 5).

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**Fig. 4: Burden of hospitalized fractures vs other disease states in Sweden**

<table>
<thead>
<tr>
<th>Hospital costs (US$ million)</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke</td>
<td>200</td>
<td>300</td>
</tr>
<tr>
<td>Myocardial infarction</td>
<td>150</td>
<td>250</td>
</tr>
<tr>
<td>Breast or prostate cancer</td>
<td>100</td>
<td>200</td>
</tr>
<tr>
<td>All fractures</td>
<td>500</td>
<td>700</td>
</tr>
<tr>
<td>Osteoporotic fracture</td>
<td>450</td>
<td>600</td>
</tr>
<tr>
<td>Hip fracture</td>
<td>300</td>
<td>400</td>
</tr>
</tbody>
</table>


**Fig. 5: Cost-effectiveness (£000/QALY gained) of treatment in women aged 50-70 years, by the presence or absence of a prior fracture and osteoporosis.**

Cost/QALY gained (£ 000)

<table>
<thead>
<tr>
<th>Prior fractures</th>
<th>T-score</th>
<th>Threshold for cost-effectiveness</th>
<th>Age (years)</th>
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<td>50</td>
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<td>55</td>
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<tr>
<td>no</td>
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<td>60</td>
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<tr>
<td>yes</td>
<td>-2.5</td>
<td></td>
<td>65</td>
</tr>
<tr>
<td>yes</td>
<td>&lt; -2.5</td>
<td></td>
<td>70</td>
</tr>
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</table>

Predicting fracture risk – the way forward

For many years, bone mineral density testing has provided the main approach to assessing fracture risk. However, recent studies have shown that prediction of fracture risk can be significantly improved by the use of specific clinical risk factors, which affect bone strength independently of bone density. Examples include a previous fracture, treatment with steroids, a parental history of hip fracture, smoking and alcohol abuse. In a new online tool, FRAX™, www.shef.ac.uk/FRAX, these risk factors are used alone or in combination with bone mineral density measurements to predict the 10-year risk of fracture. FRAX™ is becoming widely used in clinical practice and provides a basis for making decisions about treatment.

The FRAX™ tool improves the prediction of fracture risk in clinical practice, enabling more accurate targeting of treatment and resulting in greater cost-effectiveness in the prevention of osteoporotic fractures.

Paying for osteoporosis prevention and treatment saves costs associated with future fractures and saves considerable suffering and disability. Keeping our older adults free of the disability related to osteoporotic fractures seems like a wise investment.

Paying for osteoporosis prevention and treatment saves costs associated with future fractures, but importantly it also saves considerable suffering and disability associated with hip, wrist, spine, and other fractures. The importance of treating osteoporosis will only grow as populations worldwide, with increasing access to better healthcare, live longer. According to the U.S. Census Bureau, the fraction of the world’s population older than 65 (retirement age in many countries) will increase from 6% in 2008 to 15% in 2050. As countries become “older” their social welfare systems are likely to be put under greater strain. This may translate into older adults being required to remain active in the workplace for longer. Keeping our older adults free of the disability related to osteoporotic fractures seems like a wise investment.

Prior fracture, a family history of hip fracture, and steroid use are among the most important risk factors for hip fracture.

Prior fracture, a family history of hip fracture, and steroid use are among the most important risk factors for hip fracture.

*Family history
The often overlooked men with osteoporosis

Although less common than in women, osteoporosis also strikes men, causing pain, debilitation and severely impacting on quality of life – and can result in economic hardship due to the cost of treatment.

Andris, Latvia

The case of Andris from Latvia, 70 years old, shows how much-needed treatment remains out of reach for millions of people living in countries where medication is only partially reimbursed, restricted, or not reimbursed at all. About five years ago, Andris suffered from severe backache, and pain in his arms and feet. Like most people, he first went to see his family doctor, who simply prescribed pain control medication and ointments.

Some months later, while receiving medical advice for chronic lung disease, the thoracic surgeon told Andris that the bones in one of his X-rays did not look quite normal. As a result, he was sent for bone mineral density (BMD) testing. The results showed a very low bone density, a T-score of –3.0, which corresponds to severe osteoporosis. Andris was diagnosed with two spinal fractures and prescribed a bisphosphonate treatment.

The monthly cost of the medication is double that of his monthly pension income. Despite partial reimbursement, the cost of medication represents a severe financial burden on him and his family.

In Andris’ case, there was a marked improvement as a result of treatment. His bone density improved by 15% and he has experienced no further fractures. Although he still requires medication for other health problems, his overall health has improved and he no longer needs pain control medication.

This case shows that, despite some improvements in the past decade, there are obviously still many challenges for osteoporosis management in Latvia, as in other countries.

The osteoporosis experts affiliated with the Latvian Union of Osteoporosis Patients and the Association of Latvian Doctors, along with the Ministry of Health, considered the possibility of including osteoporosis medications in the list of treatments to be reimbursed by the state. Although reimbursement was considered desirable at all levels of decision making, the fact remains that in Latvia, since July 2005, only 75% of the cost of osteoporosis medication has been reimbursed.

BMD testing has been available in Latvia for more than 10 years, but unfortunately lack of awareness is still a problem and more effort needs to be made to improve awareness among health professionals and the public.

A positive step has been taken on the prevention front, where the concept of promoting healthy nutrition has been supported by the Ministry of Health. In addition, active lifestyles are being promoted with increasing attention focused on sports programmes as well as free access for the public to sports facilities.

The important role of patient societies

Often patient support groups offer the first ray of hope.

Philip, Ireland

“I started having severe back pain in October 2005 while working on a new extension to my house. I thought I had strained my back. For the next 12 months, I saw several doctors, 5 physiotherapists and a chiropractor. The total cost to me was thousands of euros to cover fees, time off work and travelling.

I continued to have severe back pain and ended up going back to my GP and insisting that I be sent for an X-ray. The X-ray came back with a recommendation that I go for BMD testing. The BMD report came back showing that I had osteoporosis. To be a 46-year old man diagnosed with osteoporosis (an “old women’s disease”), or so I thought was devastating. I was prescribed medication but I was given no advice on what to do next, nor was I told what the medication was going to do for me, or how long I would have to take it for. I was also informed that, as a bricklayer, I would never work again at my trade.

Naturally, I was very distressed and decided to be proactive. I found the number for the Irish Osteoporosis Society and phoned right away. A very helpful lady spoke to me for over an hour, explaining what osteoporosis is, the fact that it can be treated successfully, the fact that there are over 50 risk factors associated with osteoporosis, BUT that life can be got back on track. They sent me information and recommended that I see an osteoporosis specialist.

The specialist had me fill out a questionnaire to find the cause of my osteoporosis and did further testing. She contacted my GP and pharmacist personally, to explain the regular blood tests and monitoring I would need for the treatment she had recommended.

In total I was out of work for eight months but thanks to the expert help, I am back at work (being extremely careful) and the pain is tolerable. My health is improving, slowly but surely. I would recommend that anyone who has queries regarding osteoporosis contacts their national osteoporosis society.”
Improving access to osteoporosis prevention, diagnosis and treatment requires a change in political and social will. There are many powerful tools that can be employed to convince policy makers of the need to move osteoporosis higher on the healthcare agenda. We need to ensure that the health economic and socioeconomic data are presented in clear and compelling ways, and to engage with local media to show the human aspect of the disease. It is also vitally important to develop and maintain contact with key politicians, to support osteoporosis patient societies in their valuable outreach, to build partnerships with like-minded groups and to learn from successful healthcare campaigns.

Show the data in a meaningful way

Many national osteoporosis societies have carried out comprehensive health economic analyses, outlining the costs of osteoporosis in their countries and how these may be reduced by effective treatment. In 2006, IOF produced a standard template for member societies to use in the preparation of such reports to ensure that the data being collected were similar and to enable country-by-country comparisons.

Examples of successful use of these reports can be found throughout the world. In Australia, a report entitled “The Burden of Brittle Bones: Costing Osteoporosis in Australia”, has been instrumental in forcing legislators to take osteoporosis more seriously. This has led to a national action plan for osteoporosis, that has delivered several major programmes and initiatives including education and awareness campaigns, reimbursement for bone mineral density testing, and coverage for osteoporosis medicine on the Australia Pharmaceutical Benefits Scheme.

Similarly, a Canadian report, “Osteoporosis Action Plan: An Osteoporosis Strategy for Ontario” has been successful in persuading the provincial government in Ontario to adopt a progressive strategy for osteoporosis management. The report, which laid out 18 different recommendations covering education, prevention, detection, treatment, rehabilitation, and research, will lead to better testing and better access to medication. This should eventually result in fewer fractures, with projected savings of $142 million over 5 years.

In the U.S., a report11 of the Surgeon General on osteoporosis in 2004, which struck a chord amongst the public and healthcare professionals, outlined important key action steps. These include the need to increase awareness, improve the delivery of prevention and testing, continue research on prevention and treatment, support for an integrated health message and for programmes on physical activity and diet, and, perhaps most importantly, a call to act now, since more than enough is known about the problem of osteoporosis to enable implementation of effective preventive strategies.

The success of these reports has acted as an incentive for other countries. Reports are currently being drafted in South America, the Middle East and Asia. Guidelines and recommendations built upon strong scientific evidence have also been drawn up by numerous medical colleges, associations, and societies. These can be used to argue for change.
In Europe, the European Commission’s report into the status of osteoporosis in 1998 proposed eight recommendations, including adopting osteoporosis as a major health target, encouraging further research, and allocating appropriate resources to healthcare systems to deal with the growing problem. Other recommendations included the provision of bone densitometry systems for early detection, standardization of prevention and treatment strategies, and supporting the role of national patient and scientific societies. Since then, pressure for policy change has come from the European Parliament Osteoporosis Interest Group, which includes Members of the European Parliament (MEPs) from all 27 EU nations. The interest group is advised by the EU Osteoporosis Consultation Panel, a mix of policy makers and medical experts from member states. MEPs in the Interest Group actively support a range of specific actions to prevent the unnecessary suffering and expenditure resulting from osteoporosis. Some of the specific recommendations include:

- Improvement in the availability of bone densitometry resources and reimbursement for bone density scans for people at risk of osteoporosis prior to the first fracture.
- Reimbursement for proven therapies for people at risk of osteoporosis prior to the first fracture.
- Government financial support and participation in educational awareness campaigns.

A new EU audit report is currently being prepared and will be published in October 2008. Further information can be found on the IOF website.

Media events to highlight osteoporosis issues
High profile meetings such as the IOF Women’s Leaders Roundtables, which bring together accomplished women from all walks of life to help focus media and political attention on osteoporosis. Two Roundtables, held in conjunction with the 2002 and 2006 IOF World Congresses on Osteoporosis in Lisbon, Portugal, and Toronto, Canada, issued “Call to Action” documents, to encourage individuals, healthcare professionals, and governments worldwide to recognize osteoporosis as a serious global health concern. The documents specifically called for policy makers to:

- Pay for and improve availability of bone density scans for women with osteoporosis risk factors before the first fracture.
- Pay for therapies proven to prevent fractures for women with osteoporosis, before the first fracture.

The IOF has made available a tool kit to help with organizing similar events. Printed copies are available upon request from IOF.

Harnessing the political force of the osteoporosis movement
Voters and taxpayers can also bring pressure to bear for osteoporosis policy or legislative change.

Tips for approaching policy makers and ministers of health
Margaret Austin, former New Zealand Health Minister, and former Chair of the Board of Osteoporosis New Zealand, offers some insights on how best to approach health policy makers, in particular ministers of health.

“Over ten years ago I sat at a very busy Minister’s desk dealing daily with a myriad of issues, meeting with and receiving advice from departmental officials and office secretaries and hearing submissions from interested parties and organisations.

- As Health Minister, I expected organisations and individuals to be professional, to be prepared, to be succinct, to provide written outlines of their case with supporting information, to make the agenda available in advance when making the appointment.
- It helps to know the Minister’s priorities. These will have been set out in policy statements or published documents.
- It is a good idea to ask for advice on what moves to take next. It could be to meet with others in the department with health funding authorities or with those responsible for funding pharmaceuticals.
- It is really important to deal with the crucial issues or to present concrete recommendations for the Minister to consider. Hard data, good presentation and responsible requests are much more likely to generate results.
- I wanted a case being presented to provide background information, statistics, and specific requests which included costs if at all possible.
- Ministers read the papers and are addicted to news-casts. When an issue breaks they will notice and will have asked for information probably in advance of an appointment being made by the organisation.
- Finally, while support from affiliated or regional societies is good, it is likely only a national body will get access to the Minister to make the case.”
For example, in the UK, the National Institute for Health and Clinical Excellence (NICE) recently produced mandatory guidance in which treatment was restricted to alendronate, even though some people are unable to take this drug. The UK National Osteoporosis Society (NOS), together with several scientific organisations associated with bone health, successfully appealed against this guidance. Meanwhile, the National Osteoporosis Guidelines Group (NOGG) is developing evidence-based guidelines that will be launched in October 2008.

There is no “one-size fits all” strategy when it comes to lobbying for change in osteoporosis prevention, diagnosis and treatment. Hungary, for example, in 1997, achieved 90% reimbursement of medication, free DXA scans, inclusion of bone programmes in schools and implementation of a network of highly trained osteoporosis specialists due to a unique combination of political and economic factors. Although the trade-off, which would not be possible in many countries, was restricting prescription rights to some 800 specialists in designated osteoporosis care centres, this ensured that osteoporosis received far more attention in the healthcare system. Unfortunately, the reimbursement was reduced to 70% in 2007.

Making grey power heard
Since people are living longer, older adults are becoming a powerful voting block that can influence policy for the better. Sixty may be the new 50, but to be fully enjoyed those new fifties need to come without disability or lost independence. Non-government organizations dedicated to people over the age of 50 years, or those who have retired, can be influential partners in the fight for positive change in osteoporosis-related health policy. In the USA for example the AARP, formerly the American Association of Retired Persons, is one of the most powerful lobbying groups in the country and claims more than 38 million members. By joining forces with advocacy groups for the elderly (demographically a growing force) osteoporosis societies around the world can channel the increasing influence of ‘grey power’ to help ensure that osteoporosis is given priority on their government’s healthcare agendas.

Osteoporosis patient societies – helping to bring about change
Patient societies and scientific organisations can play an important role in influencing decisions about treatment and reimbursement. Much of the strength of the global osteoporosis movement resides with the people in the national societies. These committed individuals fight on the frontlines to generate public awareness, change legislation and business patterns, and mobilize support.

For example, Osteoporosis Canada’s “No Fracture is Acceptable” campaign in 2001 was carried out in four provinces, generating thousands of letters from constituents to their MPs. It resulted in an expansion of the listed drug therapies and increased access to DXA. In the USA, the National Osteoporosis Foundation (NOF), through its Bone Health Advocacy Network, encourages and facilitates direct advocacy, with “Legislative Alerts” on its website and calls for members and supporters to contact their Senators and Representatives in the US Congress.

Partnerships to maximize impact
Forging alliances with organizations with similar objectives, or which have already scored some victories in the field can help strengthen an organization’s position and garner further results. An important contribution that IOF makes to the osteoporosis effort is to help the national groups improve their professional capacity.

One example comes from Germany where the National Initiative Against Osteoporosis (NIO) is an alliance founded by the DVO (the umbrella organization of German scientific osteology-related societies), the DOP (the umbrella organization of osteoporosis self-help groups and patient societies), and the Bone and Joint Decade. By joining forces, the NIO is raising awareness of the osteoporosis treatment deficit in the country. Up to six million people in Germany are suffering from osteoporosis, making it the most common chronic disease in the country. Yet fewer than 25% of people with osteoporosis receive adequate treatment. The initiative, supported by IOF within its Invest in Your Bones Campaign, is now receiving support through an all-party interest group formed in April 2005 by prominent politicians.

Patient societies fight on the frontlines to generate public awareness, change legislation and business patterns, and mobilize support.
An example of an international partnership is found in China, where in March 2008, IOF signed a co-operation agreement with the China Health Promotion Foundation (CHPF). As per the agreement, the two foundations will co-operate in the field of osteoporosis prevention, treatment and research, as well as the promotion of public awareness of this disease in China. The President of the CHPF Dr. Bai Shuzhong said, “We attach great importance to the co-operation with IOF.” He added, “Osteoporosis has become a public health concern of the Chinese government and the Chinese people. Osteoporosis prevention and treatment is a major part of the work of the CHPF, which has set up a subcommittee on osteoporosis.”

Another example of a successful partnership which helps spread the message about osteoporosis is found in France, where an innovative “Know your risk” campaign was carried out by the Research and Information Group on Osteoporosis (GRIO) together with IOF. This was a country-wide campaign in co-ordination with the Ordre des Pharmaciens or French Council of Pharmacists (Cespharm). The campaign featured posters that raised awareness of risk factors, the IOF One-Minute Osteoporosis Risk Test was distributed across the country in pharmacies, and a technical report aimed specifically at pharmacists was sent by direct mail to all Cespharm members (i.e. all pharmacists registered in France). The second phase of the campaign, currently being implemented, will include a “roadshow” visiting 25 French cities to provide lectures and osteoporosis information to pharmacists and their staff.

Making the most of the media
Organizations fighting against osteoporosis can engage stakeholders in new and creative campaigns, as media and telecommunication technologies enable people across the world to share information, build communities, and express themselves in ways never imagined. The scope of internet and mobile telephone access is enormous and the global osteoporosis movement can leverage the access and immediacy they provide to reach new audiences and communicate more effectively with existing audiences.

At the end of March 2008, the world’s population was estimated at 6.67 billion people, with more than 21 percent, or 1.4 billion people using the Internet. Communicating the advocacy message via websites, emails or blogs, which are regularly updated, and in journals published on the web, are other tools, which may gain in importance in terms of public awareness in the future.

As part of its World Osteoporosis Day 2007 campaign, the Hellenic Society of Osteoporosis Patient Support spread its message through the Internet, as well as through traditional media. The society’s members and partners urged others to pass on a positive message, “World Osteoporosis Day is just an occasion to remind us that we have to love and care for ourselves” through a chain of emails, via blogs, and on websites. Excellent feedback was received, and many young people were reported as showing a real interest in bone health for the first time.

At the time of printing this report, the number of mobile phone users globally has reached three billion, almost
half the world’s population. An example of creative use of mobile telephones comes from Saudi Arabia where the Ministry of Health ran a national ‘SMS/texting’ drive to raise awareness of osteoporosis. According to an article in the daily ‘Arab News’ more than a million SMS text messages were sent to the public highlighting the importance of combating osteoporosis. The drive was part of a national campaign against osteoporosis, which also included distribution of a million pamphlets highlighting the importance of osteoporosis prevention throughout 20 health regions. In addition, print and electronic media carried relevant articles to keep readers and viewers abreast of the growing dangers of osteoporosis.

World Osteoporosis Day has become a focal point to draw the world’s media attention to the fight against osteoporosis. Participation in World Osteoporosis Day (WOD) has grown dramatically over the past few years with the majority of national patient societies holding WOD campaigns, reaching out to the public, media and health professionals. For the “Beat the Break” risk factors campaign launched on World Osteoporosis Day 2007, it is estimated that more than 59 million media impressions have been generated around the world.

Members of the media also have a very important role to play in speaking out for policy change. As we have seen, when it comes to both economic and personal cost, osteoporosis is comparable to many cancers and cardiovascular diseases. Reporters and news outlets have the opportunity and the resources to put osteoporosis on the right footing and patient societies are uniquely placed to help them, with concrete examples, hard data and real life stories about people who stand tall to fight osteoporosis.

Learn from other successful health lobbying campaigns
Osteoporosis and the global movement are relatively “young” when it comes to the time elapsed since the WHO defined osteoporosis, and there are lessons that can be learned from successful groups with a longer track record. The tobacco control arena, for example, has seen a great deal of global networking, information and strategy exchange over the last thirty years since the 1972 U.S. Surgeon General’s report became the first of a series of science-based reports to identify environmental tobacco smoke as a health risk to nonsmokers. Today, more than 190 NGOs are instrumental in making sure that the Framework Convention of Tobacco Control (FCTC), which was adopted in 2003 and came into force on 27 February 2005, is fully implemented.

Other disease groups, such as cancer or cardiovascular disease, are far ahead of osteoporosis in terms of widespread public awareness and use of healthcare resources. Can we learn from these groups? A simple comparison shows how much still needs to be done: Whereas most healthcare authorities consider it self evident that persons at risk of stroke are diagnosed and treated for high blood pressure BEFORE a stroke occurs, this is still not the case for osteoporotic fractures where, in many cases, patients are diagnosed and treated only AFTER a fracture occurs.

Top: Former world cup winners Rosi Mittermaier (left) and Christian Neureuther with German Federal President Horst Köhler (center) at the German National Initiative Against Osteoporosis annual marathon held for members of parliament, May 2008. Left: Crowd in Istanbul, Turkey during World Osteoporosis Day 2005 public event. Right: World Osteoporosis Day 2007 celebrations in Dubai, UAE.
Gaps in health professionals’ knowledge cause undue suffering

While osteoporosis is understood by many health professionals, many people with the condition report delays in receiving a correct diagnosis, and access to treatment often varies according to location and personal resources.

Ilona, Germany
Ilona, 58, was diagnosed with osteoporosis eight years ago. After a long and frustrating odyssey, going from one specialist to another, the cause of her unbearable back pain was finally identified as spinal compression fractures due to osteoporosis. She was shocked to realize that spinal fractures had caused her to become 8 cm shorter. Very soon after the diagnosis, Ilona experienced further spinal fractures. Plagued by fear, helplessness, and worry, she thought “there must be some way to stop this process!”

A spinal compression fracture may cause severe pain which continues for weeks or months. A patient with one or more vertebral fractures most frequently has problems with simple activities of daily living such as dressing, cleaning, cooking and washing dishes. Sport activities are impossible, social activities are difficult; this may cause feelings of fatigue, loneliness and fear of losing independence.

The orthopaedist treating Ilona prescribed a ‘supporting corset’, to be worn daily in an attempt to prevent further fractures. As medication he simply prescribed calcium and vitamin D. When asked whether anything else could be done, the specialist replied that there wasn’t and the corset would be the optimal solution.

In the months that followed her diagnosis, Ilona joined a patient self-help group under the auspices of the Bundesselbsthilfeverband für Osteoporose e.V. Her thirst for knowledge about osteoporosis and the need to share experience with other sufferers was, and is, immense. She wants to be active, to take responsibility and control of the disease.

Today she knows that there are different therapeutic possibilities and that bone-building medication is available. She has learned about bone-friendly nutrition and targeted physical exercise. The exchange of information with other people with osteoporosis and the informational seminars have given her courage and bolstered her self-confidence.

Although initially hesitant to express her skepticism to her doctor, Ilona decided to speak up, she wanted to receive the best possible therapy available. Finally, after switching to another specialist, she was prescribed appropriate medication. She continues to take an active role in controlling her osteoporosis by practicing a bone-healthy lifestyle and keeping abreast of new developments in osteoporosis management.

Ilona’s personal story shows, among other things, that the path to optimal therapy can sometimes be as long and difficult as the path to an initial diagnosis.

Osteoporosis changes lives and impacts on families

The story of Eleni from Greece illustrates the often unmeasured impact that this disease has, not just on the person with osteoporosis, but also on families and carers.

Eleni, Greece
“Following medical treatment for a gynecological disorder when I was aged 45, my doctor sent me for a bone density test. I was then diagnosed with osteoporosis.

I later experienced a serious fracture that kept me home for about six months. It wasn’t just me who was affected, but my entire family – they had to stay and care for me, at high cost to us all in terms of time, pain, patience and money.

Today I am 57 years old, and thinking back to those times, I wish I had known then what I know now. I could have done things differently. For example, as a child I always avoided dairy products. Later, after being diagnosed with osteoporosis, I didn’t have bone density measurements to monitor whether my situation was worsening.

Now I realize how important it is that someone with osteoporosis, and his or her family members, keep informed about the disease. Through my local osteoporosis patient society I regularly receive news about osteoporosis, falls and fractures, exercise, nutrition, etc.

Of course, I make sure to follow my doctor’s advice and never forget my therapy. I’ve become more careful and feel safer.

If I had to give advice to others I’d say that prevention is the most important thing. Fractures, the result of osteoporosis, are the worst – but they just signal the beginning of other problems like lack of independence and work, social life, friends…”
What You Can Do

Individuals
The general public can work for change at several levels. At national, state, and local levels, people can take a variety of steps, including lobbying lawmakers and health officials, advocating for increased funding, establishing patient alliances, assisting in educational outreach, raising awareness, and working with the media. Individuals can also assist and support their national osteoporosis societies.

In addition, there are various actions that can be taken at a personal level to help promote bone health.

- Make it your policy to have a good diet rich in calcium and vitamin D, and to take regular exercise. A healthy diet and weight-bearing exercise can help prevent osteoporosis and the falls that lead to fractures. The IOF ran a three-year lifestyle campaign to focus attention on diet, exercise, and risk factors and published three popular reports that offer valuable insight and advice. “Bone Appétit”, “Move it or Lose it”, and “Beat the Break – Know and Reduce Your Osteoporosis Risk Factors” can be found on the publications section of the IOF website.
- Take the IOF One-Minute Osteoporosis Risk Test on the IOF website and seek your doctor’s advice if you think you are at risk.
- Consult your doctor about a bone mineral density scan, which is the gold standard for risk assessment.
- Ask your doctor to avail of the free FRAX™ fracture risk assessment tool to evaluate your personal risk of getting an osteoporotic fracture. Many people who find out that they are at increased fracture risk modify their lifestyle and so can reduce their risk in that way.

Healthcare Professionals
Doctors, nurses, nutritionists and other healthcare professionals with expertise in bone health also have an important role to play both as caregivers and advocates. Healthcare professionals are encouraged to use the new FRAX™ tool, which takes into account modifiable and fixed risk factors, and BMD (if available), and estimates the probability that a given individual will sustain a fracture within the next 10 years.

Healthcare professionals should also seriously consider setting up or using existing fracture liaison services. Studies show that as few as 10% of people who sustain a fracture receive follow up testing for osteoporosis but fracture liaison services, conceived in the late 1990s, have been very successful in identifying people who need follow-up bone mineral density scans or treatment for osteoporosis in several countries. Studies have shown that this service can almost triple the number of fracture sufferers receiving bone mineral density scans and significantly increases the number of individuals receiving appropriate treatment.

Upcoming Latin American and Asian Reports

In December 2008, IOF will release a report on osteoporosis in the Asian region. The report aims to assess the current status of osteoporosis across Asia, to identify care gaps and challenges, as well as provide recommendations and solutions. To date, there is a serious lack of Asia-specific osteoporosis data and osteoporosis competes for scarce healthcare resources with many other serious health issues in the region. The IOF Asian Osteoporosis Report will provide much needed data to help national osteoporosis member groups convince policy makers about the personal and economic burden that the disease causes throughout Asia. Similarly, more data are also needed for countries in Latin America. IOF is currently working with patient societies in Mexico and Argentina for the production of a report for each of these two countries. These reports, due for release in the summer of 2009, will assess the current status of osteoporosis, identify where gaps exist and make recommendations for future actions, thus providing essential information to help move osteoporosis higher on healthcare agendas.

We must grasp opportunities to educate health policy decision makers about osteoporosis and its burden on society, to ensure a better deal for people with osteoporosis.
Stand tall, speak out for bone health

The best way we can get the message to health policy makers is to communicate our stories. We have the facts and figures and know that scientific evidence alone is rarely enough to achieve a policy change. We know that more needs to be done to promote early diagnosis and offer reimbursement for proven therapies before the first fracture. We must grasp opportunities to educate the health policy decision makers about osteoporosis and its burden on society, to influence health policy, and to ensure a better deal for people with osteoporosis. We need to stand tall and speak out for our bones!

We must ensure that osteoporosis is prioritized and sufficiently recognized in health and social care policy around the world. It is time to stand tall, to speak out for bone health.

IOF Policy Toolkit

IOF has produced the IOF Policy Toolkit, which is a guide to mobilize IOF member societies and the global osteoporosis movement. It is intended to assist member societies to act as advocates in the preparation and delivery of key osteoporosis messages.

The IOF ‘Invest in your bones’ publications are issued on World Osteoporosis Day in support of IOF member activities around the world and are translated into many languages.

2001 Bone Development in Young People
2002 Osteoporosis in the Workplace
2003 Quality of Life
2004 Osteoporosis in Men
2005 Exercise: Move it or Lose it
2006 Nutrition: Bone Appétit
2007 Risk factors: Beat the Break
2008 Policy change: Stand Tall, Speak Out


In partnership with:

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Bone & Joint Decade

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