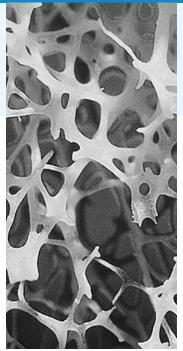
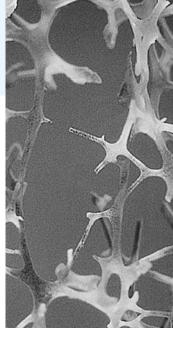


## What is Osteoporosis?

Osteoporosis, which literally means "porous bone", is a disease in which the density and quality of bone are reduced. As the bones become more porous and fragile, the risk of fracture is greatly increased. The loss of bone occurs "silently" and progressively. Often there are no symptoms until the first fracture occurs, frequently as a result of a simple fall.

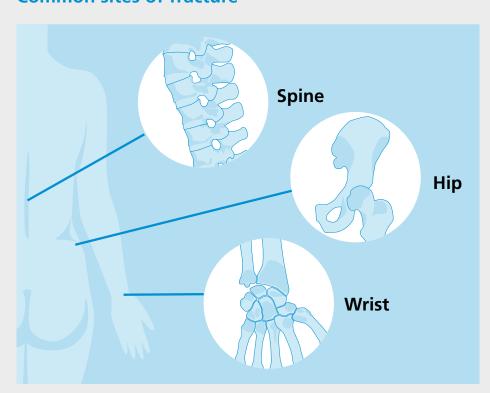




**Normal bone** 

Osteoporotic bone

#### **Common sites of fracture**



The most common sites for fractures associated with osteoporosis are the hip, spine and wrist. The incidence of these fractures, particularly at the hip and spine, increases with age in both women and men, beginning at about age 50.

Of notable concern are vertebral (spinal) and hip fractures. Vertebral fractures can have serious consequences, including loss of height, intense back pain and spinal deformity. In addition to significant suffering, osteoporotic vertebral and hip fractures are associated with increased mortality. Hip fractures are associated with reported mortality rates up to 24% in the first year after a hip fracture<sup>1</sup>. Following a hip fracture only one third of patients return to their former level of independence<sup>2</sup>.

# Osteoporosis in the European Union in 2008: Ten years of progress and ongoing challenges



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## Message from the President of the International Osteoporosis Foundation



Professor John Kanis

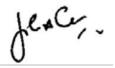
# The body of evidence that has been published about osteoporosis prevention, diagnosis, epidemiology and treatment over the past 10-15 years is extensive. Thanks to the scientific community's continued research, we have the ability to identify and treat individuals before they suffer fractures – the debilitating outcome of osteoporosis.

Today we know that without intervention the first fracture is associated with an 86% increased risk of a subsequent fracture<sup>3</sup>. However the great majority of individuals at high risk (up to 80%), who have already had at least one osteoporotic fracture, are neither identified as being at high risk, nor treated<sup>4</sup>. Thus, despite our ability to identify high risk individuals and prevent further fractures, we are seeing an increase in the number of osteoporotic fractures.

The toll these fractures take is significant. For sufferers it can mean loss of independence, long term pain and disability, and premature disruption in workplace productivity resulting in lost income or years of life in a long-term care facility. Fractures account for a significant proportion of a government's health budget. This encompasses both acute and chronic medical costs resulting from all fractures and especially those of the hip which require hospitalisation, rehabilitation and other after-care.

Yet this is a disease that can be largely prevented through timely diagnosis and cost-effective treatment. In the long run, this saves money as well as preventing the suffering imposed by these fractures.

I emphasize the urgent need to involve all stakeholders in a coordinated effort to address the care gaps outlined in this report.



## Message from the European Parliament Osteoporosis Interest Group Co-chairs



Angelika Niebler MEP, Germany



Mary Honeyball MEP, UK

Today, despite great improvements in our knowledge of osteoporosis and its management, there are still significant care gaps in most European countries.

A 55-year old woman slips on a small patch of ice, and ends up in the local hospital with a broken wrist. Consider these two "scenarios" – the first of which is still all too common

Scenario no. 1: The attending physician applies a plaster, and sends her home with instruction to return in six weeks for the plaster removal. There is no follow-up. However just a few years later the woman experiences another far more serious and costly fracture. Scenario no. 2: Following application of the plaster, this same woman is advised by her physician and attending staff that because of her age and nature of the low-trauma fracture, she may have osteoporosis. A bone density test is ordered, and a follow-up visit to her primary care physician, who identifies a low bone density and because of other risk factors that have been identified, starts the patient on a bone healthy plan of exercise, calcium, vitamin D and proven medication regimen.

We would like to see Scenario no. 2 become the automatic, and universally accepted, model of care. There is a very good chance this intervention will stop the 'fracture cascade' before it begins – saving this patient from a future of pain and loss of good health, independence and other more severe fractures, and, at the same time, saving the healthcare system thousands of euros in medical treatment.

We urge our colleagues in the European Parliament to join the EP Osteoporosis Interest Group. Together we can ensure that osteoporosis is placed on healthcare and social agendas, and that the European Union can lead the way to making osteoporosis a priority in each member state.

Superha Willer Many homesbau

## Introduction from the Chair of the EU Osteoporosis Consultation Panel



Professor Juliet Compston

In 1998, following troubling statistics about osteoporotic fractures and the rising personal and financial toll this was taking, a working party of experts, set up by the European Commission Directorate General V, published "Report on Osteoporosis in the European Community: Action for Prevention". The aim of the report was, in addition to providing a detailed analysis of the epidemiology, pathogenesis and clinical management of the disease in the European Union, to provide a number of specific recommendations which were primarily targeted at improving prevention of osteoporosis in the future. These **Eight Recommendations** identified key targets for the improvement of osteoporosis management in all member states and remain, to this day, the cornerstone of what needs to be achieved.

In 2001, with funding from the European Community and supported by the International Osteoporosis Foundation (IOF), a report entitled "Osteoporosis in the European Community: A Call to Action" was prepared by a working group representing the 15 countries in the EU at the time. The report indicated that while progress had been made in some areas, significant care gaps still existed, especially regarding the accessibility to diagnostic assessment and treatment before the first fracture occurs. In response to these findings an informal, all-party group, the European Parliament Osteoporosis Interest Group was formed to promote health policy at all levels of government. Shortly after, the EU Osteoporosis Consultation Panel was established, with membership comprised of scientific and policy experts from each member state. Since 2001 the Consultation Panel and Interest Group have met on an annual basis to develop policy strategies that look to address gaps in the care of osteoporosis at European, national and local levels.

In 2007, IOF recognised that the landscape of osteoporosis management in Europe had changed since the 2001 audit. There were now 27 member states in the EU reflecting a larger, more comprehensive population. With this in mind, IOF requested that the Consultation Panel carry out this new evaluation of the current standards of osteoporosis management with a view to assessing what progress has been made and what still remains to be done.

As Chair of the EU Osteoporosis Consultation Panel, I am encouraged by the progress shown in this report. I applaud the many collaborative activities among my colleagues to promote policy change. The committed efforts from members of the Consultation Panel, the scientific community, national patient groups and parliamentarians have certainly made gains, but the results of these efforts are mixed. We can see that slowly but surely some EU member states have added osteoporosis to their health priorities, while most have not. Access to timely bone densitometry testing has improved, along with proven therapies, but there is significant inconsistency throughout Europe, and bone density testing and treatment are not universally reimbursed despite the presence of risk factors.

While some member states have made remarkable progress in osteoporosis prevention and treatment policy, many aspects of osteoporosis management remain unsatisfactory and much remains to be done. This comprehensive snapshot will enable national governments to assess current progress and to identify areas that require more attention.

I invite scientists, physicians, policymakers, advocates, and patients and their families, as well as concerned EU citizens, to use the information in this report to identify those issues that need attention now, and encourage them to follow through with scheduled meetings with their parliamentarians, local representatives and the media. The active support of all citizens of the European Union, and the governments of its member states, is essential if the important goals which remain outstanding are to be realised.

Volid Capan

## The Burden of Osteoporosis

Aside from its personal and human cost, osteoporosis is a major public health problem, with enormous social and economic impact. Worldwide it is estimated that one in three women and one in five men over the age of 50 will sustain an osteoporotic fracture. In the European Union, someone has a fracture as a result of osteoporosis every 30 seconds<sup>5</sup> and with an increasingly larger ageing population, the yearly number of hip fractures alone in the EU is expected to more than double over the next 50 years<sup>6</sup>.

In the year 2000 in Europe, there were an estimated 3.79 million osteoporotic fractures, of which 0.89 million were hip fractures (711,000 in women and 179,000 in men)<sup>7</sup>. The combined risk of fractures coming to clinical attention is around 40%, equivalent to the risk for cardiovascular disease<sup>8</sup>. This report captures only the annual number of hip fractures among European Union member states, rather than all of Europe, and suggests an incidence that continues to increase.

Collection of data for hip fractures is easier than for other fractures, because they require hospitalisation and are thus captured in hospital records. We know that only half of the hip fracture patients who survive will walk again, but often not to the same degree as before the fracture<sup>9</sup>.

Although osteoporosis can be easily diagnosed and treated, studies have shown that it remains seriously underdiagnosed and under-treated. It is estimated that only one out of three vertebral fractures comes to clinical attention<sup>10</sup>. Despite this, it is known that having one vertebral fracture increases the risk for sustaining additional vertebral fractures five-fold within the next year<sup>11</sup> a phenomenon commonly known as the 'fracture cascade'. Even in patients who present with a clinically evident fracture, appropriate diagnostic testing and

The burden of osteoporotic fractures on healthcare budgets is greater than for breast and prostate cancer, myocardial infarction and approaches that for stroke.

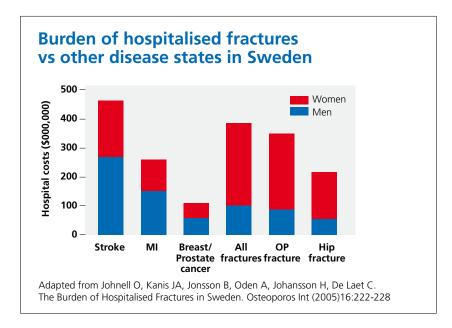
treatment for osteoporosis are provided in only about 20% of cases.

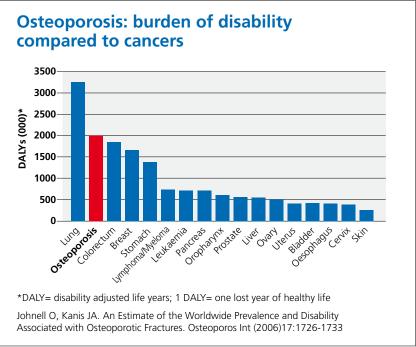
In Europe, osteoporotic fractures are responsible for a higher disease 'burden', in terms of disability and excess mortality, than common cancers with the exception of lung cancer. The global burden of a disease, as seen in the graph below, is often measured in DALYs, or disability adjusted life years. 1 DALY equals one lost year of healthy life.

Furthermore, in women over 45 years of age, osteoporosis accounts for more days spent in hospital than many other diseases, including diabetes, myocardial infarction and breast cancer, and ranks

high among diseases that result in people becoming bedridden with serious complications.

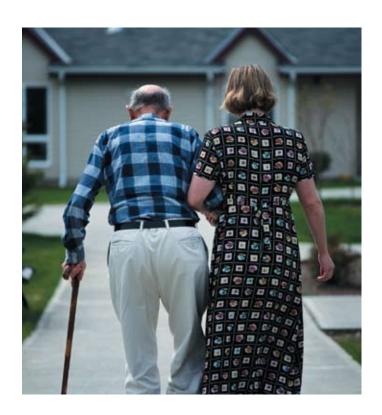
Despite these statistics, many countries continue to place osteoporosis low on the list of priorities in their healthcare agendas (see Recommendation 1, page 9). While osteoporosis may not be perceived to have the mortality and morbidity of other chronic diseases, it is clear that the burden is in fact comparable or greater. It is expected that other EU countries would mirror the trends shown in the results of the Swedish study in the graph below.

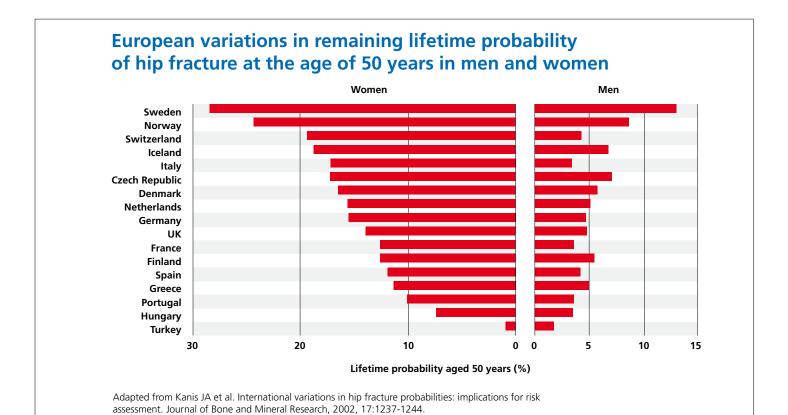




# Only half of the hip fracture patients who survive will walk again, but often not to the same degree as before the fracture.

Estimates for hip fracture incidence are more complete than for other fractures, and we know that the majority of hip fractures in those over age 50 occur as a result of osteoporosis. The graph below suggests that for men and women who reach the age of 50, the remaining lifetime probability of sustaining a hip fracture varies significantly among countries worldwide. For example, the probability of a 50 year old woman from Sweden sustaining a hip fracture during her remaining lifetime is 28% compared to 10% for a woman in Portugal. This variation is related more to hip fracture incidence than to variations in mortality risk<sup>12</sup>.





## Osteoporosis in the European Union in 2008: Ten years of progress and ongoing challenges

#### Why now?

The IOF, the European Union Osteoporosis Consultation Panel, and the European Parliament Osteoporosis Interest Group now have several years of policy effort to be proud of. There have been substantial advances in osteoporosis health policy – from increased numbers of diagnostic scanners to enhanced awareness among governments to growth in national osteoporosis societies. However, there are still individuals at high risk of fragility fractures who are not being identified, are not referred for treatment, or have little or no access to established treatments.

Since the early reports, the European Union has nearly doubled from 15 to 27 member states. This 2008 report, now encompassing the 'new' member states, is more reflective of osteoporosis in Europe today.

The report is intended to provide a snapshot of conditions through the European Union today. Even though comparative data are available for the original 15 members only, it offers an instructive tool for assessing

progress made and opportunities for further policy work in all countries. Detailed individual country reports can be reviewed on the IOF website: www.iofbonehealth.org



"Action needs to be taken now to improve strategies to prevent osteoporosis to avoid the predicted increase of EU citizens who will suffer from fractures.

By moving policy action forward, we will make a difference to the lives of millions of Europeans."

Mary Honeyball, MEP UK, Co-chair EP Osteoporosis Interest Group

In Europe, the size of the population is expected to increase by 26% in women and 36% in men between 2000 and 2050. The increase will be most marked in elderly people at the age when hip fractures are most common.

## Projected percentage increase in population in Europe by age category\*

Calendar year	Men 50+ (99433)	Women 50+ (130786)	Men 65+ (41032)	Women 65+ (66146)	Men 80+ (6205)	Women 80+ (15042)
2000	0	0	0	0	0	0
2010	15	12	12	8	49	38
2020	29	22	34	23	85	61
2030	37	28	60	42	122	81
2040	42	31	75	52	187	130
2050	36	26	81	55	239	160

\*Population (in thousands) shown in parentheses as at 2000.

Kanis JA on behalf of the World Health Organization Scientific Group (2007) Assessment of osteoporosis at the primary healthcare level. Technical Report. WHO Centre for Metabolic Bone Diseases, University of Sheffield, UK 2007, p. 38.

#### 1998



2001



2002



Since the launch of the eight recommendations by the European Commission in 1998, IOF and the EU Osteoporosis Consultation Panel have launched five policy action reports. A first "audit" report measured and compared indicators of progress against the 1998 recommendations. This 2008 report is the first to include current data for all EU members, and comparative figures for the original 15 member states.

## **Objectives of the Report**

#### The objectives of this report are to:

- Provide a comprehensive snapshot of current osteoporosis management in the European Union.
- Review the individual and comparative status of fracture incidence, costs, access to and reimbursement for bone density testing and treatments, funding support for national societies, educational programs and research.
- Acknowledge areas of progress, and identify care gaps that prevent early diagnosis and treatment of those at risk of fracture.
- Create a policy tool for all stakeholders (health care professionals, policy makers, advocates and patients) to address those care gaps.
- Provide detailed information relating to each country in the EU. Although not included in this printed report, the individual country reports can be downloaded from the IOF website: www.iofbonehealth.org/policy-advocacy.





Since 2001, annual meetings of the EU Osteoporosis Consultation Panel and EP Osteoporosis Interest Group have taken place in Brussels and Strasbourg



#### **Acknowledgement of Authors**

We wish to thank the EU Osteoporosis Consultation Panel members for their significant contributions in providing national data for this report. This represented a considerable commitment, given other demands on their professional and personal lives.

Panel membership is comprised of scientific experts and policy experts from each EU member state who serve on a voluntary basis. Some have served as representatives since the original 2001 audit, and are highly committed to the work required to provide optimal care to patients at risk. Others have joined over the years as the EU expanded, and have shown the same commitment to making osteoporosis a major health concern in their country.

All agree to the common goal of developing and delivering practical, cost effective strategies to improve access to diagnosis and proven therapies before the first fracture.

During annual meetings of the Panel, presentations have been given to further the understanding of risk factors for fracture, life style modifications for risk reduction, prevention, best practice therapies and the healthcare costs required to meet growing numbers of hip fractures. In addition, a hands-on workshop was held in April 2007 to better explain how to navigate the EU parliamentary system for effective advocacy.

For a complete list of EU Consultation Panel members, see page 24.

## Recommendations from the 1998 "Report on Osteoporosis in the European Community – Action for Prevention"

### **8 Recommendations**

These 8 Recommendations, from the 1998 European Commission "Report on Osteoporosis in the European Community – Action for Prevention", have provided the foundation for subsequent policy work in the European Union and continue as a framework for this 2008 report.

**Recommendation 1** Osteoporosis is to be adopted as a major healthcare target by the EU and governments of all the member states.

**Recommendation 2** More information is required about the incidence and prevalence of osteoporotic fractures.

Recommendation 3 Coordinate national systems throughout the EU to plan effectively for increase in demand for healthcare and to institute appropriate resource allocation.

Recommendation 4 Develop and implement policies to advise the general public and health professionals about calcium and vitamin D nutrition.

**Recommendation 5** Access to bone densitometry systems should be universal for people with accepted clinical indications and reimbursement should be available for such individuals.

Recommendation 6 Member states to use an evidence-based approach to determine which treatment should be advised. Reimbursement should be available for all patients receiving treatment according to accepted indications.

Recommendation 7 Governments should actively promote national patient and scientific societies, providing financial support and helping to publicise their cause. Appropriate training of healthcare professionals involved in the management of osteoporosis should also be an important priority.

**Recommendation 8** Further research is required in all areas of bone health in general, and osteoporosis specifically.



"In 1998 the European Commission's report stressed the need for co-ordinated efforts among stakeholders across the European Union to avert the impending epidemic of osteoporotic fractures. Fortunately, the past decade has seen an increasing consensus among the public, policy makers, and health care professionals that action must be taken."

Professor Socrates Papapoulos, EU Osteoporosis Consultation Panel Senior Advisor

### **Recommendation 1:**

## Osteoporosis, a Healthcare Priority

A major objective of IOF's policy work in Europe has been to make the prevention of fractures due to osteoporosis a government healthcare priority in all European Union member states.

Is osteoporosis a healthcare priority? When this question was first asked in the 2001 osteoporosis audit, not one of the 15 EU member states (shown in red font in the graphs and charts throughout this report) reported that their governments had targeted osteoporosis as a priority. Some governments viewed osteoporosis as a 'concern', others incorporated osteoporosis as part of a broader healthcare mandate, while most did not include it at all in their agendas. Even in 2001, strong evidence about risk factors and the importance of screening were available, and proven therapies for prevention and treatment were on the market throughout Europe, yet most governments chose to reimburse diagnosis and therapy only after a fracture had occurred.

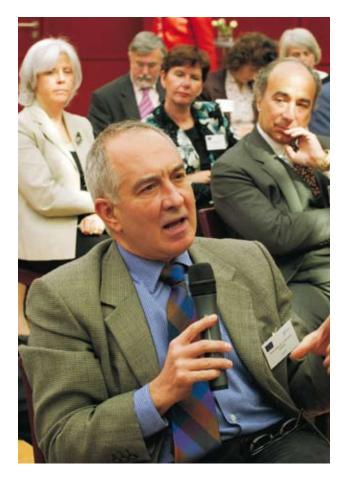
Only six out of 27 member states have declared osteoporosis a national healthcare priority.

**Osteoporosis Healthcare Priority** 2007 Government supported osteoporosis campaigns **Austria** Belgium Bulgaria Cyprus Czech Rep Denmark Estonia **Finland** France Germany Greece Hungary Ireland Italy Latvia Lithuania Luxembourg Malta Netherlands **Poland Portugal** Romania Slovakia Slovenia Spain Sweden yeslimitednodata not reported Ref: As reported by EU Osteoporosis Consultation

Panel Members in 2007

Today it is reported that governments in only six of 27 member states have declared osteoporosis a national healthcare priority – partial success with a long way to go.

Unless osteoporosis prevention and treatment become a priority for governments and healthcare providers, the growing number of osteoporotic fractures will have a serious impact on society, not just in terms of people's quality of life, but also in regard to the increased costs incurred for acute healthcare, rehabilitation and nursing care.



### **Recommendation 2:**

## **Fragility Fractures**

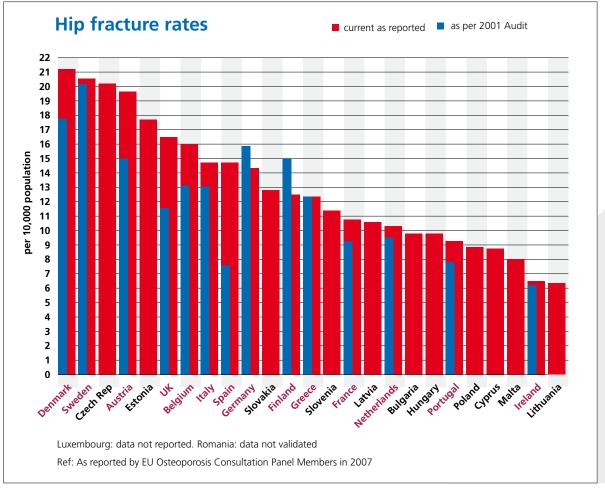
Osteoporosis has no symptoms prior to the first fracture. Fragility fractures are defined as those that occur as the result of low trauma (for example a fall from standing height or less) or trauma that in a healthy individual would not cause a fracture. There are often no symptoms prior to the first fracture, with most fractures occurring at the hip, spine and wrist.

There are wide differences in hip fracture incidence throughout the world. The highest incidence has been observed in northern Europe and USA. However, even within Europe there is variation, for example rates vary approximately ten-fold between Sweden and Turkey<sup>13,14</sup>.

The table below summarises the hip fracture incidence in EU member states today. When compared to the data captured for the EU members listed in our 2001 audit report, it clearly indicates rising fracture rates by as much as 30-100%.



Hip fracture incidence has risen significantly since 2001, with dramatic increases seen in Spain, UK and Austria.



# Recommendation 2: Fragility Fractures

Hip fractures are associated with serious disability and reported mortality rates of up to 20-24% in the first year after the fracture.

#### **Economic burden of fractures:**

Osteoporotic fractures create an enormous burden on healthcare budgets. In Europe, direct medical costs for osteoporotic fractures are estimated at more than 36 billion euros annually<sup>15</sup>. The huge costs associated with hip fractures include hospitalisation and after care costs of rehabilitation. Duration of hospital stay varies from 3 days to many weeks or even months, with the average around 10 days. The number of days in rehabilitation facilities ranges from 10 to 48, averaging 20 days.

Assessing the economic burden of fractures is complicated, mostly due to the lack of national fracture registries or standardised tracking systems. Healthcare costs differ greatly, as do standards of care. However, because hip fractures, unlike vertebral or wrist fractures, almost always result in hospitalisation and require surgery in the vast majority of cases, their incidence and related costs are easier to monitor.

For example, the average length of hospital stay following a hip fracture is 8 days in Slovakia, 13.9 days in France, and 26 days in the United Kingdom with costs per day of 38 euros, 720 euros and 426 euros respectively. These reported direct hip fracture costs vary depending on national standards, and may or may not include any combination of in-hospital costs such as surgical options, physician and other healthcare professional fees, or pharmacologic treatment. Hip fractures also account for additional costs due to post-hospital care. These estimates are also inconsistent, and may include a variety of post-acute services such as physical therapy, home nursing, care in a long term facility, other rehabilitation and medicines.



Therefore, the reported cost of hip fractures to the healthcare system likely underestimates the real economic burden of fractures.

Hip fractures are associated with serious disability and reported mortality rates of up to 20-24% in the first year after the fracture, often as the result of other health complications<sup>16,17</sup>.

Most fractures follow a fall from a standing position. The risk of falling increases with age and is slightly higher in elderly women than elderly men. Only half of the hip fracture patients who survive will walk again, but often not to the same degree as before the hip fracture event<sup>18</sup>.

The projected increase in the ageing population will lead to an increasing frail population at greater risk of falls and fractures.



"It is important to stop the 'fracture cascade' before it begins. This will save fellow citizens from a future of pain and loss of good health and independence

whilst in addition saving the health care system thousands of euros in medical treatment."

Angelika Niebler MEP, Germany Co-chair EP Osteoporosis Interest Group

# Recommendation 2: Fragility Fractures

Within the first year following a vertebral (spinal) fracture one in five women will experience an additional fracture resulting in what is called the 'fracture cascade'. These fractures can result in pain, loss of height, spinal deformity and loss of independence. Vertebral fractures often go undetected, are rarely reported by physicians and remain ignored. Fewer than 10% of vertebral fractures result in hospitalisation, even if they cause pain and substantial loss of quality of life<sup>19</sup>.

The economic burden of vertebral fractures arises mainly from outpatient care, nursing care, and lost working days.

Likewise, while wrist fractures are most common in women aged 45 to 65 and signal a risk for future fractures, there is little awareness among the medical community to refer these women for osteoporosis assessment.

The huge economic burden of vertebral fractures does not arise mainly from hospital costs, but rather from outpatient care and lost working days.

## Hospital costs per vertebral fracture in the European Union

Country	Cost per vertebral fracture (thousand euros)	<b>Length of stay</b> (days)
Austria	2.7	8
Belgium	4.3	16
Denmark	3.0	14
Finland	2.8	13
France	6.1	20
Germany	4.4	17
Greece	0.4	5
Ireland	3.6	8
Italy	2.1	7
Luxembourg	3.0	12
Netherlands	3.9	14
Portugal	1.4	12
Spain	2.6	10
Sweden	4.0	9
UK	3.5	15
European Union	3.9	13

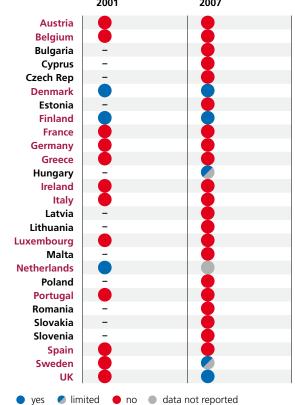
Adapted from Kanis JA on behalf of the World Health Organization Scientific Group (2007) Assessment of osteoporosis at the primary healthcare level. Technical Report. WHO Centre for Metabolic Bone Diseases, University of Sheffield, UK 2007, page 43.



#### **National fracture registries**

National fracture registries need to be established throughout the EU to plan for the increased burden of fractures in the healthcare system, and to allocate appropriate resources. This report reveals that in 2007 only four EU member states supported this process, with others tracking fracture activity via hospital records only.

# Fracture registry Has a national fragility fracture registry been established for data collecting and monitoring? 2001 2007



Ref: As reported by EU Osteoporosis

Consultation Panel Members in 2007

### **Recommendation 3:**

## Co-operation, Support and Funding

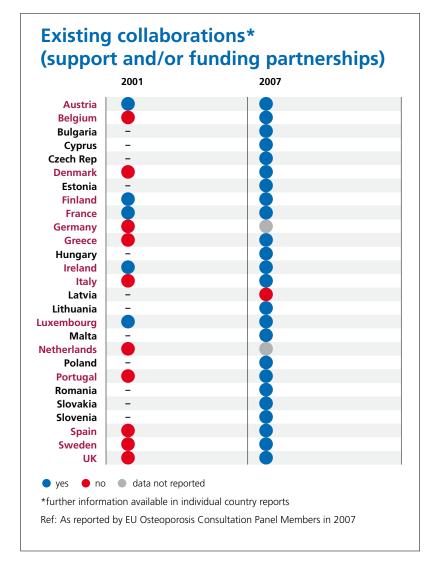
National osteoporosis societies have been established in all EU countries, providing educational, scientific and policy support. Despite small operating budgets and volunteer staffing from the medical and public sectors, these organisations have achieved considerable results in healthcare and public education on bone health, risk factors, prevention, guidelines, new research, and media awareness programmes.

Programmes like this cannot happen without collaboration and support among all stakeholders in the osteoporosis community. Co-operative partnerships in funding and other resource allocation can help improve the delivery, integration and quality of osteoporosis education.

The chart below illustrates how collaborations have increased in the years since the 2001 audit. It is obvious that all stakeholders are fully aware of the importance of working closely together to enable change and improvements to take place. Further details of individual cooperation, support and funding can be found on the country reports on the IOF website.







### **Recommendation 4:**

### Calcium and Vitamin D

Developing and implementing calcium, vitamin D and nutrition recommendations is fundamental to any osteoporosis prevention and treatment programme for all age groups.

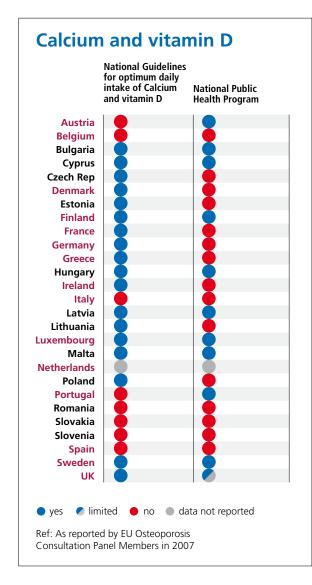
Beginning in childhood, establishing adequate nutritional intake of calcium and vitamin D as well as regular exercise is key to developing peak bone mass at around the age of 20-25 when the growth process of bones is completed. Peak bone mass is the maximum bone mass achieved in life.

In younger and older adults, nutrition plays a role in preserving bone mass and strength, and aids recovery in those who have suffered a fracture. Calcium and vitamin D supplementation reduces rates of bone loss and reduces fracture rates in the frail elderly population<sup>20,21,22</sup>.

While playing a major role in establishing and maintaining bone health, calcium and vitamin D intake among all age groups is often suboptimal.

Many EU member states have participated in some form of calcium and vitamin D awareness campaigns, including school, healthcare professional, public health, or media programmes, but few have implemented national guidelines for its citizens. Government supported guidelines create a consistent and targeted message to all age populations, and are key to the acceptance of bone healthy diets.

In 2001, calcium and vitamin D education was generated by osteoporosis patient societies or scientific organisations only. None of the 15 members reported government supported programs. Today 18 of 27 member states have national guidelines for the optimal intake of calcium and vitamin D, but only 10 have established national public health programmes that incorporate this information.





More than half of the member states have established calcium and vitamin D guidelines. However, further efforts towards guideline dissemination and implementation need to be made.

# **Recommendation 5: Bone Densitometry**

Osteoporosis is defined as "a systemic skeletal disease characterised by low bone mass and microarchitectural deterioration of bone tissue with a consequent increase in bone fragility and susceptibility to fracture"<sup>23</sup>.

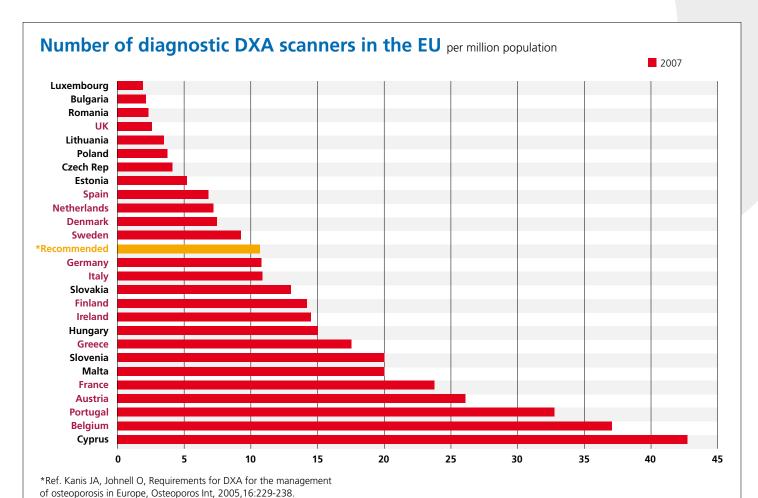
The current gold standard for assessing bone mineral density (BMD) is dual energy X-ray absorptiometry (DXA), a technique which measures the bone mineral content of the skeleton, typically of the lumbar vertebrae and hip. DXA measurements are used for the diagnosis of osteoporosis and, together with a clinical assessment, are used to assess the probability of future fractures. DXA may also be used as a tool for monitoring response to treatment. DXA measurements have been shown to be related to fracture risk, i.e. the lower the bone density, the higher the risk for fracture. It is important that DXA measurements be incorporated into the identification of all risk factors for fracture. This non-invasive technique is available throughout the EU.

More than 40% of EU member states have fewer than the recommended number of DXA scanners.

Ref. as reported by EU Osteoporosis Consultation Panel Members in 2007

While the recommended number of DXA scanners per million population is 10.6, the graph below shows that almost 40% of EU member states fall below this target. Overall however, despite increased number of scanners over the years, barriers to its usefulness continue, including availability, accessibility, cost, limited reimbursement and extensive waiting time.





# Recommendation 5: Bone Densitometry

Since the 2001 Report, progress has been made throughout the EU to increase the number of DXA scanners. However, barriers to universal accessibility do remain. Despite the additional number of scanners, in many countries the majority of machines belong in the private healthcare system with few dedicated to the public system. This creates longer waiting times for those without insurance or other government allowances.

Restricted reimbursement is a significant obstacle to accessibility and utilisation. Reimbursement criteria for bone density tests vary among EU member countries, often with ineligible criteria for patient compliance as a screening tool for osteoporosis. For information as to whether reimbursement is full or partial and for the actual criteria per country, please visit the IOF website to download the individual country reports.

Geographic distribution is problematic as many smaller cities and towns, and especially rural communities, are well below the recommended number of scanners per population.

To fully assess bone mineral density and identify those for whom prevention and early detection of low bone density can prevent the first fracture, DXA scans must be made more readily available to reduce waiting times and there should be open access to reimbursement for all EU populations.

The charts on this page summarise average cost, reimbursement and wait times for DXA assessment.

Full reimbursement for DXA is provided in only 9 of 27 EU member states. DXA scans must be made more readily available to reduce waiting time and there should be open access to reimbursement for all EU populations.



#### Cost of DXA / waiting time in the EU Waiting time in the public **Cost in Euros** health system in days 35 7-14 **Austria Belgium** 40 40 – 60 nil Bulgaria Cyprus 70 90-120 20 Czech Rep 7-21 200 Denmark 28 17 Estonia 60-90 0-100 **Finland** 0-3 39.96 14-21 France 30-40 Germany <10 104 Greece 50 Hungary 25 14-56 20-140 140 Ireland Italy 75-82 1-168 Latvia 20-50 7 Lithuania 15-25 14 not available 7-28 Luxembourg 50 – 75 Malta 180 **Netherlands** 100 7-90 9-40 30-90 **Poland** 10.5-150 Portugal 5-30 Romania 15-60 nil Slovakia 30 14-21 30-50 Slovenia 10 Spain 90-120 153 Sweden 180 14-180 69 UK

Ref: As reported by EU Osteoporosis Consultation Panel Members in 2007

#### Identifying those at risk of fracture

According to the WHO criteria, osteoporosis is defined as a BMD of 2.5 standard deviations or more below the average value for young healthy women (a T-score of ≤-2.5). This measurement has provided a diagnosis threshold, as well as an indication for pharmacological treatment. There are, however, limitations to the use of BMD alone as a diagnostic tool. DXA scans are not always accessible, especially in rural regions of Europe, nor are they always eligible for reimbursement. But most importantly, BMD alone may not detect those at high risk of fracture. The recently published "WHO Scientific Group Technical Report: The Assessment of Osteoporosis at the Primary Health Care Level" identifies factors other than BMD that contribute to fracture risk. These independent risk factors can be used to support BMD test results, or used to predict fracture risk in the absence of BMD tests.

The algorithm is the basis of a newly developed practical web-based tool, available at www.shef.ac.uk/FRAX. FRAX® is a significant development for clinical practice as it helps identify which individuals would most likely respond to pharmaceutical management, while avoiding unnecessary treatment in others. Clinical practitioners simply enter an individual's risk factors into the FRAX® tool. These factors include age, bone mineral density, body mass index, prior fragility fracture, ever use of oral glucocorticoids, parental history of fracture, current smoking, alcohol intake and rheumatoid arthritis.

The European Guidance for the Diagnosis and Management of Osteoporosis in Postmenopausal Women was recently published by the European Society for Clinical and Economic Aspects of Osteoporosis and Osteoarthritis (ESCEO). The paper assesses diagnostic methods, treatments and their monitoring options, providing a roadmap for European countries to practically implement the new FRAX® tool<sup>24</sup>.



"The Fracture Risk Assessment Tool (FRAX®) has been developed for use in primary care settings to support the identification of those at risk

for fracture and the selection of appropriate treatment."

Professor Pierre D. Delmas<sup>†</sup>, IOF Founding President



#### Risk factors for osteoporosis

There are both fixed and modifiable risk factors which are associated with osteoporosis. Although 'fixed' factors (which include age, gender, and family history) largely determine whether a person is at increased risk of osteoporosis, 'modifiable' factors (like nutrition and exercise) play a key role as well. People who have many of the modifiable or fixed risk factors listed below, should consult with their doctor about having a BMD scan and possible use of the FRAX® tool to assess their fracture risk.

Fixed risk factors include:

- Age
- Female gender
- Family history
- Previous fracture
- Race/ethnicity
- Menopause/hysterectomy
- Long term glucocorticoid therapy
- Rheumatoid arthritis
- Primary/secondary hypogonadism in men

Modifiable risk factors include:

- Excessive intake of alcohol
- Smokina
- •Low body mass index
- Poor nutrition
- Vitamin D deficiency
- Eating disorders
- Insufficient exercise
- Low dietary calcium intake
- Frequent falls

Reference: www.iofbonehealth.org

### **Recommendation 6:**

### **Prevention and Treatment**

The goal of all osteoporosis management is to prevent that first fracture, followed by effective management of those fractures that have occurred. Several successful treatment options have been developed to maintain bone density and reduce the risk of fractures, and are widely available throughout Europe.

Different studies have consistently shown that, depending on the drug and the patient population, treatment reduces the risk of vertebral fractures by between 30-65% and of nonvertebral (including hip) fractures by between 16-70%<sup>24,25</sup>. Just as high blood pressure is treated to prevent stroke, and cholesterol levels are lowered to prevent heart disease, the risk of osteoporotic fractures can be greatly reduced through medication.

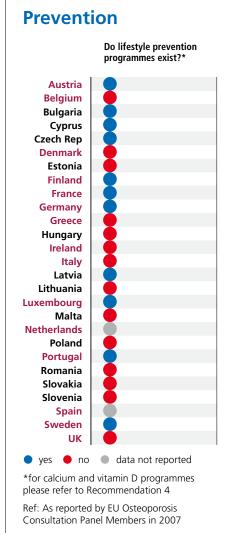
The identification and treatment of patients at risk of fracture, but who have not yet sustained a fracture, will substantially reduce the long term burden of osteoporosis. Reducing the risk of first fracture from 8% to 2% can reduce the 5-year fracture incidence from approximately 34% to 10%<sup>26</sup>.

In many countries, partial reimbursement may not be enough to guarantee access to treatment. For a retired person on a meagre state pension even 75% reimbursement may far exceed their economic capacity to pay for medication, including calcium, vitamin D supplements etc. This places a great financial burden on the individual and their family.

National healthcare systems approve not only which treatments are the most effective and safe for the prevention and treatment of osteoporosis, but determine which patient populations will receive reimbursement for that treatment. There are several effective treatments and dosing regimens available throughout Europe today, allowing physicians to select the most appropriate choice for their patient needs.

Patients are required to take osteoporosis medication for many years to achieve successful fracture prevention and reduction. While compliance is dependent on several factors, patients faced with high medication costs often decide to stop taking their treatment. This interruption in treatment could result in high fracture rates and costs in the future.





Despite the efficacy, safety and availability of proven treatments, accessibility is restricted to much of the population in Europe, mainly due to cost and restrictive criteria for reimbursement.

## Recommendation 6: Prevention and Treatment

The chart on page 18 indicates that most EU members support some degree of reimbursement for the most effective treatments, but many require the presence of a fragility fracture and low T-score to qualify. Far fewer health programs provide these treatments to those at high risk before the first fracture occurs, with most giving partial payment only. The criteria for reimbursement vary among countries, from low T-scores to selected risk factors, and may include a reduced number of treatment options.

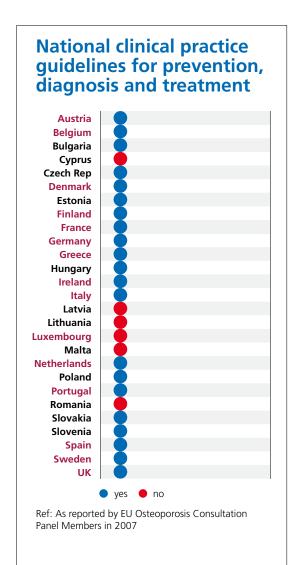
Only when policy makers and health authorities increase accessibility to treatment before the first fracture will the human and economic costs associated with osteoporosis be reduced. As indicated on page 17 of this report, in addition to national guidelines, the European Guidance for the Diagnosis and Management of Osteoporosis in Postmenopausal Women also provides guidance on this subject.



Clinical practice guidelines are now available in the majority of EU member states. In order to achieve their full potential, the guidelines must be widely disseminated and implemented in clinical practice.

### Clinical practice guidelines

Clinical practice guidelines on the management of disease, including osteoporosis, are the accepted method of providing consistent care. Relying on a rigorous, evidence-based review of the research literature by experts in the field, guidelines provide a high standard of care for all levels of healthcare professionals, healthcare administrators, organisations and societies, and healthcare policy makers. Evidencebased guidelines are a key component to improving the quality of care across all healthcare settings and should, where possible, be underpinned by cost-effectiveness analysis. The information should be objective, clearly stated for professionals and patients, and incorporate regular updates. The majority of EU member states have developed osteoporosis guidelines, many of which have been appraised according to the AGREE Collaboration (Appraisal of Guidelines for Research and Evaluation), an instrument which provides a framework for systematic quality assessment of guidelines. A list of guidelines in European countries can be viewed on the IOF website www.iofbonehealth.org.



## **Recommendation 7: NGO Support**and Healthcare Professional Education

Improved access to diagnosis and treatment alone are not enough.

Musculoskeletal diseases in general, and osteoporosis specifically, are frequently given a lower level of priority compared to other clinical areas in the medical education system. A post-menopausal woman with a low trauma fracture, for example, may never be advised to have a bone density test to assess for osteoporosis, yet there is a 25% chance she will return with another fracture within one year.

Increased attention to osteoporosis in medical teaching programs will prepare clinicians and other healthcare professionals to effectively identify and treat those at risk for fractures.

One quarter of EU member states report minimal or no standardised training programs for professionals, several others receive training from national

Almost one quarter of EU member states report minimal or no standardised teaching programs for healthcare professionals. osteoporosis societies only. Training and certification of all professionals, from clinician to DXA technologist to rehabilitation therapist, are essential to create and maintain a standardised level of expertise and patient care.

Public education on bone health, including prevention and treatment of osteoporosis, is often accomplished through the work of national osteoporosis societies. All educational material must be translated and communicated to the public ensuring that everyone understands how to promote bone health in the early years, maintain bone density throughout adulthood, and most of all how to prevent and reduce fractures. EU Consultation Panel individual country reports show a critical under-funding of societies by governments with only 8 of 27 EU governments providing funds to keep these societies active. These educational programs must be sustained.

The support of health policy makers and parliamentary officials will ensure that healthcare providers are professionally equipped to provide early diagnosis, identification of risk factors for fracture and appropriate treatment. The bottom line: fracture prevention can save governments millions of euros per year.



### **Recommendation 8:**

### Research

Research in a wide variety of bone-related fields is being carried out in clinics, research institutes and universities throughout Europe. Current research areas include: bone biology, genetics, ageing, biomechanics, epidemiology of fractures and osteoporosis, bone imaging, orthopaedics and fracture healing, pathophysiology, nutrition and vitamin D, rehabilitation and exercise.

The EU Consultation Panel urges research to continue with emphasis on the following:

- Development of national fracture registries. Data on the prevalence, mortality, morbidity and associated costs will not only create a vital monitoring system, but allow governments to better prepare for sustained healthcare funding support
- Further identification of risk factors for fractures.
   Targeted prevention for those at high risk will reduce the growing burden of fracture costs
- National and international collaboration for continued work on therapeutic options, including vitamin D, calcium and exercise
- Secondary causes of bone loss



### **Personal Stories**



Philip Byrne, Ireland "In total I was out of work for eight months due to osteoporosis. I am back working (being extremely careful) and the pain is tolerable, slowly but surely

improving...If I had not contacted them (the Irish Osteoporosis Society), I would have been unable to support myself and would have been in severe pain till I ended up in a wheelchair ..."



Ann Manley, Ireland

"At age 23, I was thinking of having fun with friends, not fractures. To be told at this age that my bones were more osteoporotic than those of my seventy

year old mother was something of a shock to say the least. I had been diagnosed at age 20 with anorexia nervosa and had thought little of the consequences of this condition until I was advised by my doctor to go for a DXA scan. I have also tried to make the medical profession, of which I am a part of, and other eating disorder sufferers aware of osteoporosis and the fact that it can have an effect on any age group and either sex."



Eleni Kipriotaki, Greece

"After being diagnosed with osteoporosis I experienced a serious fracture that kept me at home for about six months. The problem

was that 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..."



Jouko Numminen, Finland

"I am 57-years old and was finally diagnosed with severe osteoporosis only after decades of painful fractures... Although osteoporosis had been diagnosed, the official medical center could offer me very little information. I was lucky that I was accepted for a self-help course where I met people who

were in the same position as I was. After discussions together and lessons held by professionals, I found out how I could cope and move forward with my life."



#### Carmen Sanchez, Spain

"As it is common in people of a certain age, I attributed my back pain to the "ageing effect". But as time went on it was more difficult to

do daily tasks at home and I lost agility and mobility...It's hard to believe now, but it took me more than two years to have access to a DXA test. Bureaucracy, lack of means, ignorance about the illness were, in my opinion, the main reasons why I had such difficulty in getting a test which should be accessible to any woman susceptible of suffering osteoporosis... Fortunately, my life has changed from those years. Currently I'm taking adequate treatment that has really helped me to improve my health. I'm also more aware of the importance of doing sports and taking care of my diet. All these are very important weapons in the fight against osteoporosis."

## **Achievements and Ongoing Challenges**

Definite progress has been shown in many countries since 2001, but there are still major gaps in care that deny many people the opportunity for timely and appropriate management to prevent fractures. Failure to implement today's knowledge into practice will lead to increasing numbers of fractures in our ageing population and huge economic costs for our overstretched healthcare resources. When compared to the 2001 audit report, data collected in 2007/2008 show:

#### **Achievements**

- The importance of osteoporosis as a health priority has been recognised by a number of European states.
- The number of days in hospital following hip fractures has been reduced, often by more than half, reducing that portion of the health budget.
- School programs have been developed in several countries, focusing on increased bone healthy food choices and dairy products, often replacing fast food and soft drinks.
- Shorter waiting times for DXA scans have been achieved in many countries, ensuring more efficient diagnosis and treatment. However, this often applies to major cities only those in less populated regions still have extensive waiting times due to lack of local DXA equipment.
- Effective, evidence-based treatment options have increased in the past ten years.
- National osteoporosis societies now exist in every EU member state. These organisations
  provide awareness, support and education for both the public and healthcare professional populations, ensuring continued attention to the needs of those with osteoporosis.
- Overall an increase in national programs has allowed for promotion of awareness, prevention, healthy lifestyle, diet including calcium and vitamin D, and treatment.

#### **Ongoing Challenges**

- With only 6 of 27 governments declaring osteoporosis a healthcare priority, it continues to remain an under-funded, under-identified, and under-treated condition. Further progress cannot be made until all national governments and the EU make osteoporosis and its resulting fractures a healthcare priority.
- Hip fracture costs have doubled or tripled in several countries.
- Targeted identification and early treatment of those at risk for fractures could save governments millions of euros per year, and untold pain and suffering for patients.
- National and EU-partnered fracture registries must be established to accurately document the burden of osteoporotic fractures and to assess progress in their prevention.
- Full access to and reimbursement for bone density scans and proven treatments must be made available to high-risk individuals in all countries.

#### **Policy tips**

This report can be used to mobilise health policy makers in your country! Perhaps you can start by creating a one-page overview that summarises the report's key messages and findings, especially those relating to your country. Focus on two to three key messages that express care gaps in your country and be sure to repeat these messages throughout your policy campaigns.

#### Analyse:

- How does your country compare to other EU countries?
- How can the information from this report be incorporated into other policy documents and activities?

#### Mobilise:

- Encourage the members of your national society to make advocacy a priority within the organisation.
- Identify and invite key health policy officials, members of parliament (national and within the European Parliament) to be your osteoporosis advocates.
- Arrange meetings with policy makers go well prepared and keep it short and focused.
- Use the media invite journalists to report on the findings in this report or provide articles to magazines, newspapers and journals.

## **European Union Osteoporosis Consultation Panel Members:**

The EU Osteoporosis Consultation Panel, convened in 2001, brings together policy makers and osteoporosis experts from the member states. Their mandate is to work with stakeholders at both national and EU levels to implement practical, cost-effective strategies to improve access to diagnosis and proven therapies before the first fracture.

#### **Consultation Panel Chair**

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#### Consultation Panel Senior Advisor

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### Consultation Panel Co-ordinator

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Hon. Prof. Dr. Robert Schlögel Federal Ministry of Health and Women

#### **Belgium**

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#### Denmark

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Dr Daniel Navid CEO, International Osteoporosis Foundation

# The European Parliament Osteoporosis Interest Group

The EP Osteoporosis Interest Group is an informal, all-party group founded in 2001 to stimulate policy developments at both national and European levels by increasing political awareness about osteoporosis, participating in policy activities, and supporting relevant legislation. They are the 'voice' of osteoporosis on key government and public health committees, representing the scientific and public communities.







## **EP Osteoporosis Interest Group Members** as at June 2008

Co-Chairs: Angelika Niebler MEP, Germany and Mary Honeyball MEP, UK Vice-Chairs: Dorette Corbey MEP, the Netherlands Péter Olajos MEP, Hungary

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"We should realise that the fight against osteoporosis is a social movement, and all social movements in history were born of a crisis."

> Her Majesty Queen Rania of Jordan IOF Patron



#### **Acknowledgement**

IOF thanks the EU Osteoporosis Consultation Panel members for their significant contributions in providing national data for this report. Panel membership is comprised of scientific experts and policy experts from each EU member state who serve on a voluntary basis. We also thank the patients who have kindly contributed their personal stories.

Complete Reports from each EU member state can be seen on the IOF website: www.iofbonehealth.org



The International Osteoporosis Foundation (IOF) is the only non-governmental organization dedicated to the global fight against osteoporosis. IOF brings together scientists, physicians, patient societies and corporate partners. Working with its 186 member societies in 90 countries around the world, including EU member states, IOF encourages awareness and prevention, early detection and improved treatment to prevent osteoporotic fractures in individuals at high risk.

The vision of the IOF is a world without osteoporotic fractures.

#### Mission

- To increase the awareness and understanding of osteoporosis.
- To support national osteoporosis societies in order to maximize their effectiveness.
- To motivate people to take action to prevent, diagnose and treat osteoporosis.

#### Goals

- Nurture and enlarge the IOF network of member societies worldwide.
- Promote medical innovation and improved care.
- Expand IOF partnerships with organizations working on similar or complementary issues and projects.
- Lobby for policy change in all countries so that diagnosis and treatment of osteoporosis becomes routine.