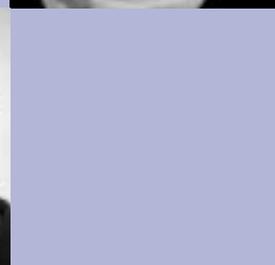
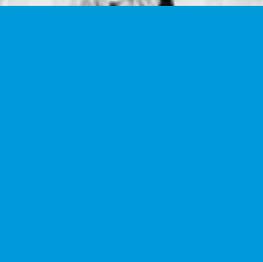


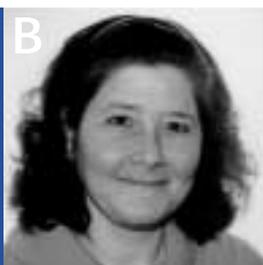
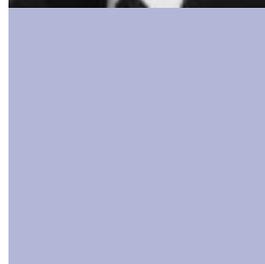
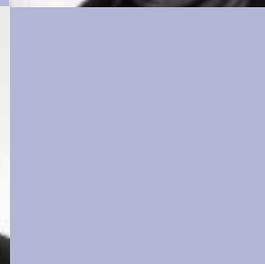
# Osteoporosis in the European Community: A Call to Action

An audit of policy developments since 1998

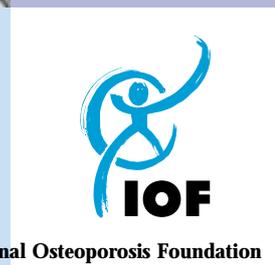
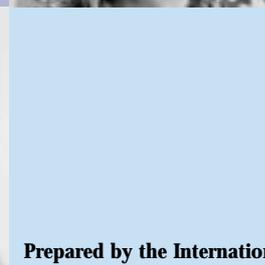


“Osteoporosis affects millions of Europeans. It’s time now to take serious action to stop the human suffering resulting from this disease.”

Mel Read, MEP, Founding Chair of the European Parliament Osteoporosis Interest Group



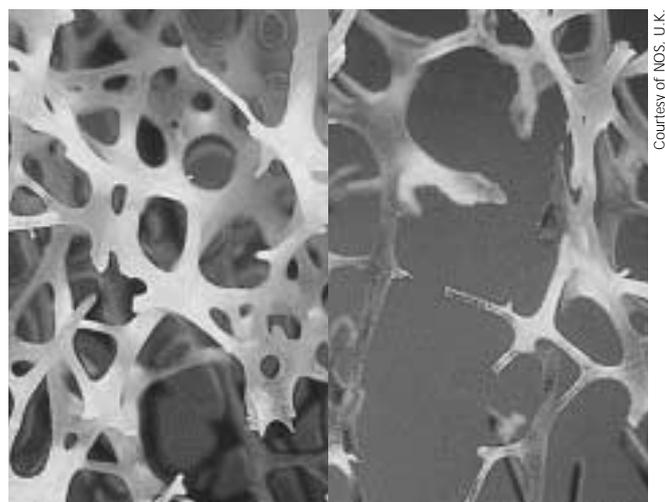
Photos on the cover show people at risk of, or with osteoporosis – full stories inside.



Prepared by the International Osteoporosis Foundation

# Osteoporosis – “the silent epidemic”

Osteoporosis is defined by the World Health Organization as a systemic disease characterised by low bone mass and micro-architectural deterioration of bone tissue, leading to enhanced bone fragility and increased fracture risk. The loss of bone mass occurs progressively and “silently” – until the first osteoporotic fracture occurs. Fragility fractures are the hallmark of osteoporosis and are particularly common in the spine, hip and forearm. These fractures show a steep age-related increase and have a major impact on the health of elderly populations.



Healthy bone

Osteoporotic bone

Women with postmenopausal osteoporosis frequently experience fractures in their vertebrae as they age. A prevalent vertebral fracture is one of the most important risk factors for future spine and hip fractures. A five-fold increased risk has been shown in developing subsequent fractures within one year after the first fracture. Multiple vertebral fractures can lead to height loss, a curved back, chronic back pain and loss of independence. Hip fractures are the most serious type of osteoporotic fracture: they are especially disabling and, together with vertebral fractures, are associated with a substantial increase in death.

## Who is at risk?

One in three women and one in eight men over the age of fifty will be affected by osteoporosis.

It is estimated that in the European Community alone someone has a fracture as a result of osteoporosis every 30 seconds.

The yearly incidence of hip fractures in the European Community is expected to more than double, from 414,000 to 972,000 over the next 50 years.

Measurement of bone mineral density (BMD) is critical to the diagnosis of osteoporosis. According to the recommendations of a WHO working group, osteoporosis was defined in white

women (the sub-population for which there is the most data) as a BMD of 2.5 standard deviations or more below the average for the young healthy female population. This same BMD value is being provisionally used for men, as data on BMD and fracture in men are still scarce. For each standard deviation decrease in BMD, fracture risk increases by approximately 200–300%. Measuring BMD is the single best predictor of fracture risk and is comparable to measuring blood pressure to predict stroke and is substantially better than measuring serum cholesterol to predict cardiovascular disease.

Although bone loss occurs rapidly in women during the menopause (a logical time to prevent bone loss), routine screening by BMD is not justifiable for all postmenopausal women. To improve cost effectiveness, other risk factors should be taken into account to determine whether BMD measurement for diagnostic purposes should be recommended for any one person.

Simple check-lists are available such as the International Osteoporosis Foundation's “One-Minute Osteoporosis Risk Test” which can indicate whether the person may be at risk of osteoporosis and whether a doctor should be consulted.

## **BMD measurement to diagnose osteoporosis is recommended in the presence of any of the following risk factors:**

- Radiographic evidence of osteopenia (i.e. reduced BMD) and/or vertebral deformity
- Loss of height, dowager's hump (after radiographic confirmation of vertebral deformity)
- Previous low-trauma fragility fracture especially of the spine or wrist
- Prolonged corticosteroid therapy (prednisone, or equivalent, 7.5 mg daily with an expected use of 6 months or more)
- Premature menopause (age <45 years)
- Prolonged secondary amenorrhea (>1 year)
- Primary or secondary hypogonadism
- Chronic disorders associated with osteoporosis: anorexia nervosa, malabsorption syndromes including chronic liver disease and inflammatory bowel disease, primary hyperparathyroidism, post-transplantation status, chronic renal failure, hyperthyroidism, prolonged immobilization, Cushing syndrome
- Maternal history of hip fracture
- Low Body Mass Index (<19 kg/m<sup>2</sup>)

Men and women with BMD values more than 2.5 standard deviations below the mean for young females (i.e. osteoporosis) should be offered appropriate information, support and treatment. Individuals with osteopenia and with additional risk factors that suggest a heightened risk of fracture should also be offered the same options. The use of BMD measurement to target treatment in this way costs less than the treatments given on the basis of risk factors alone and is justified from a health economic perspective. However, further research is needed to optimise strategies for diagnosis and treatment of osteoporosis. Additionally, newer diagnostic methods, such as ultrasound and biochemical markers of bone turnover, need to be further validated and their practical use in the diagnosis of osteoporosis clearly defined.

# Osteoporosis in the European Community: A Call to Action

An audit of policy developments since 1998

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# Introduction

We live in challenging times.

With so many important global problems why should policy makers pay attention to osteoporosis? The primary issue for IOF is that osteoporosis causes a huge amount of human suffering, and that it doesn't have to be that way.

Osteoporosis, which affects one in three women in Europe and one in eight men, is a disease which can, to a certain extent, be prevented. It can be easily and painlessly diagnosed. And it can be effectively treated. At each medical conference we receive more information about the cascading nature of osteoporotic fractures. One new study, for example, presents particularly disturbing data – once a woman suffers her first vertebral fracture there is a five-fold increase that she will suffer a second fracture within a year. It is therefore essential to prevent that first fracture.

Obviously osteoporosis is serious and devastating. So why haven't European governments done more to stop this silent epidemic? That's the question that millions of European voters and taxpayers are increasingly asking. Why don't the policy makers listen to peoples' voices and change government policies on paying for appropriate diagnosis and treatment? Why don't government agencies do more to promote awareness about the disease?

I urge you to read this audit report, which reviews achievements (or lack thereof) since the 1998 European Community report was published. You will see that while there has been some progress in some countries, by and large governments – at the national and European levels – have not responded to the will of people.

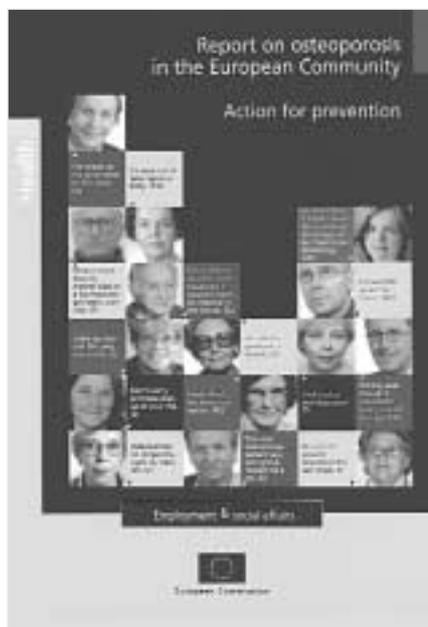
We congratulate Commissioner Byrne and his colleagues for supporting this audit, and we look forward to being able to give our supporters good news in several years – that European and national health care officials have established osteoporosis as a key issue on the public health agenda.



Professor Pierre D Delmas, MD, PhD  
President, International Osteoporosis Foundation



Report on Osteoporosis in the European Community: Launch meeting / press conference at the European Parliament in Brussels on 10 June 1998



In 1998, Europeans read in the launch materials for the *Report on osteoporosis in the European Community* about the human suffering and economic toll caused by osteoporosis, which was characterised as a “silent epidemic”. Regrettably, the public debate about this widespread disease is still all too silent, although the individual stories of people who live with the disease speak eloquently about the need for action. What has happened to the people profiled at the time of the 1998 report?

- Anna Richman’s osteoporosis is under control – she has completed medical school and lives a busy, active life.
- Hans van den Brink can’t help his wife, who is confined to a wheelchair, because he’s “afraid of fracturing another bone.” His son and daughter have osteoporosis but have been advised by their doctor to keep their condition quiet, to avoid discrimination in getting insurances and mortgages.
- Inger Lundegaardh has had a second hip replacement. She tells other women: “If you think you need a bone density test, don’t leave your doctor’s office until he gives you what you demand.”
- And Egle Pezzota still can’t hug her granddaughter because Egle is afraid of breaking her bones.

Their full stories, and those of other Europeans, can be found in this audit. These 15 people represent the millions of human stories of people in Europe who are at risk of osteoporosis or who suffer from this disease. These people represent a social movement that is growing both in numbers and in its efforts to change public healthcare systems so that people are made aware of the disease, that doctors recognise those at risk of osteoporosis and that healthcare systems pay for appropriate diagnosis and treatment.

For number crunching economists, there are impressive arguments for diagnosing and treating osteoporosis. The figures from 1998, which are certainly higher today, indicate that osteoporosis costs national treasuries over €3,500 million annually in hospital healthcare alone. Osteoporosis patients currently occupy more than 500,000 hospital bed nights per year in the European Community. And the lifetime risk of a hip fracture in women is greater than the sum of the lifetime risks of having breast, endometrial and ovarian cancer. The sad fact is that osteoporosis remains silent, overlooked, under-diagnosed and under-treated. What can we do?

The European Commission welcomes this new IOF audit report *Osteoporosis in the European Community: A Call to Action*. The new public health programme which is currently being discussed in the European Parliament and Council has several elements connected with osteoporosis. Firstly, as regards data collection, the Community will aim to create a much more user-friendly and dynamic data collection and health information system. The future programme will also seek to address health promotion and disease prevention through action on health determinants. Osteoporosis affects millions of Europeans. It’s time now to do what we can at the appropriate level to prevent the unnecessary human suffering resulting from this disease, particularly by means of prevention and information campaigns and reinforcement of the efforts of patient groups.

David Byrne  
Member of the European Commission



# Background

*The Report on osteoporosis in the European Community – Action for prevention*, a European Commission publication, was launched at the European Parliament in June 1998. It contains detailed information about osteoporosis and specific recommendations aimed at reducing the burden of osteoporotic fractures and improving the quality of life of those who suffer from the disease. The full report and a summary document were published in all 11 official languages of the 15 European Union member states and disseminated throughout relevant professional, political and patient support organisations. The Report stresses the need for co-ordination of efforts across the European Union and the importance of raising the profile of osteoporosis amongst the public, politicians, media and health professionals.

The recommendations produced as a result of the Report emphasised the inequality of access to diagnostic facilities and treatments throughout the European Union member states and stressed the need for the European Parliament explicitly to recognise osteoporosis as a major healthcare priority. Information available about prevalence and incidence of osteoporotic fractures varied widely between member states and the recommendation was made that a co-ordinated system should be set up for monitoring fracture rates at both national and European Union levels. In view of the predicted demographic changes over the next few decades resulting in an ageing population and the corresponding dramatic rise in number of osteoporotic fractures, the importance of effective planning and reallocation of healthcare resources to meet the increasing demands was stressed. The role of nutritional factors in skeletal health was acknowledged and the development of policies to promote adequate intakes of calcium and vitamin D recommended.

Significant deficits in the provision and reimbursement of bone densitometry measurements to diagnose osteoporosis were identified throughout the member states and the recommendation was made that these measurements should be accessible and reimbursed for all individuals with accepted risk factors for osteoporosis. The need for more standardised treatment strategies throughout the European Union was emphasised, with reimbursement for all those receiving treatment according to accepted indications. The vital role of national patient and scientific societies in the support and education of those affected by osteoporosis and their carers was acknowledged; the importance of government support for these groups and appropriate training of all health professionals involved with the disease was stressed. Finally, the need for research in a number of areas was identified, with emphasis on prospective studies involving collaboration between European Union member states.

At the time the Report was published, the need for continuing and critical evaluation of progress in acting upon the recommendations was recognised in order to achieve the ultimate objectives of reducing the incidence of osteoporotic fractures and improving quality of life for those affected by the disease. The International Osteoporosis Foundation has therefore conducted an audit to assess the progress made in the three years since publication of the Report. The purpose of this audit is to establish the changes that have been made as a result of the recommendations and to identify areas in which further action is required. This will define priorities for the future and enable continuing progress to be made in reducing the enormous and increasing burden attributable to osteoporotic fractures.

“The purpose of this audit is to establish the changes that have been made as a result of the recommendations and to identify areas in which further action is required.”



Dr Juliet Compston  
Co-editor of the 1998 *Report on osteoporosis in the European Community*.

# Recommendations

from the 1998 Report on osteoporosis in the European Community

## ***Recommendation 1***

Osteoporosis is to be adopted as a major healthcare target by the EU and governments of the 15 member states.

## ***Recommendation 2***

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

## ***Recommendation 3***

Co-ordinate 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 urgently required in a number of areas, including:

- Modifiable determinants (such as exercise and calcium intake) of peak bone mass and how these might be used to achieve higher peak bone mass in the population.
- Identification of risk factors for falling and the effects of fall prevention strategies on fracture.
- Additional evaluation in different age groups of approaches to identify individuals at risk from fracture, for example the use of broadband ultrasound attenuation, biochemical markers of bone turnover and risk factors, either singly or in combination.
- Assessment of the cost/utility ratio of screening in older women.
- The causes and treatment of osteoporosis in men.



## OVERVIEW

National population	8,110,244	
Population over 50	2,666,831	
Number of hip fractures in 1998	12,000 (est.)	15 (per 10,000 population)
Number of hip fractures in 2000	No information available	
Total direct hospital costs of hip fractures	€156,000,000 (1998)	

### Recent major achievements

- The Austrian Green Cross for Preventive Medicine established the Institute for Osteoporosis Prevention to help implement the recommendations in the 1998 *Report on osteoporosis in the European Community*. The programme of activities the institute runs is called *Action for Healthy Bones – No Chance for Osteoporosis* (Aktion Gesunde Knochen – Keine Chance für Osteoporose).
- The Institute for Osteoporosis Prevention, together with the Austrian Society for Bone and Mineral Research, has organised a new nationwide osteoporosis patient society (Dachverband der Österreichischen Osteoporose Selbsthilfegruppen), with the aim of co-ordinating local patient groups throughout the country. In 1998 there were only 2 small patient groups in Austria, now there are 14 very active ones and another 4 are starting up.

### Important setbacks

- Financial support for the implementation of the 1998 report recommendations is not generous enough.

### What action needs to be taken

- Expand the network of patient societies.
- Define quality standards for diagnosis and treatment of osteoporosis.
- Improve reimbursement for DXA (bone density) measurement.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

No, osteoporosis is not a priority. For this reason the Austrian Society for Bone and Mineral Research funded working groups to improve the situation of osteoporosis in Austria, for example in defining quality standards for diagnosis and treatment. The Institute for Osteoporosis Prevention was established to aid implementation of the 1998 report recommendations.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?*

In Austria every hip fracture that comes to hospital attention is recorded by use of the ICD 10 international coding system for medical diagnoses.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

Please refer to data in the 1998 *Report on osteoporosis in the European Community*.

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

Please refer to data in the 1998 *Report on osteoporosis in the European Community*.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?*

The Institute for Osteoporosis Prevention is supported by grants from pharmaceutical companies (MSD, Eli Lilly and Roche), Austrian milk organisations and from state funding via the National Funding Organisations (Fond Gesundes Österreich).

*How has the budget changed since 1998?*

The average annual budget is €75,000. In 1998 it was nil.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

Education about the importance of calcium and vitamin D local activities occurs in a number of ways: at World Osteoporosis Day events throughout the country, through regular training courses for officials of patient societies and at training courses and meetings for physicians, organised by the Austrian Society for Bone and Mineral Research and the Institute for Osteoporosis Prevention.

### Recommendation 5

#### ACCESS TO BONE DENSITOMETRY SYSTEMS

*Number of hip and spine DXA units per million population (as at beginning of 2000).* 11

*Average cost in € per DXA scan of the hip and spine (public and private health systems).*

Public: free. Most people in Austria receive medical care under the public health system.

Private: €70 (total cost). Approximately 50% is reimbursed by the health insurance systems.

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).*

Public: full cost paid directly.

Private: approximately 50% is reimbursed by health insurance systems.

*Average waiting time for DXA scan (public and private health systems).*

Public: 4–12 weeks.

Private: 4–12 weeks. The waiting time for a bone scan can be a little shorter in private institutions but 4–12 weeks is the average.

### Recommendation 6

#### PREVENTION/TREATMENT AND REIMBURSEMENT

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care?*

The Austrian Society for Bone and Mineral Research has produced guidelines, which are updated on a regular basis.

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

The costs of diagnosis (except DXA scans) and treatment are generally paid in full by the health insurance systems.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?*

No, as long as the treatment regime is based on a reliable diagnostic procedure. After appropriate diagnosis, registered drugs for the prevention of osteoporotic fractures are free of charge for the patient. Fortunately, in Austria, the patient does not have to have a fracture before costs are covered.

### Recommendation 7

#### THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS

*Has the government actively supported (financially or through public information) national patient and scientific societies?*

Yes, for example, awareness-raising activities during World Osteoporosis Day such as cooking for healthy bones. However, a majority of the funding for implementing the 1998 report recommendations has come from the pharmaceutical industry.

*Do appropriate training programmes for healthcare professionals exist?*

Yes, organised by the Austrian Society for Bone and Mineral Research and the Institute for Osteoporosis Prevention.

### Recommendation 8

#### RESEARCH

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

- Follow-up to the European Vertebral Osteoporosis Study (EVOS) and European Prospective Osteoporosis Study (EPOS) to update epidemiological data.



#### Patient story

June 1998

Karin Palmer contrasts her situation to that of a football player who crashes to the ground hand-first.

“The football player gets up and continues to play,” she says. “I crashed to the floor of a supermarket and broke my wrist.” Mrs Palmer has the symptoms of osteoporosis but has never been diagnosed as having the disease. She fractured her left wrist after falling on an icy pavement. Eight months later, while the left wrist was still only partly healed, she fell at the end of a supermarket escalator and broke her right wrist. “It had no protective sidepanels at the point where it ended,” she says, arguing that the absence of such devices can be a major health hazard. Both wrists remain weak. “Twenty months after the first accident I was walking in the mountains,” Mrs Palmer remembers. “I came to a passage where I had to support myself on a rocky path. I couldn’t continue – I couldn’t put even the slightest weight on my hands.” Since Mrs Palmer’s fractures seem to indicate osteoporosis, she underwent a bone density scan. Fortunately, her bones are fine and she does not have osteoporosis. Nevertheless, she follows a course of osteoporosis prevention and is careful about what she eats. She supplements her diet with calcium, magnesium and other vitamins and minerals.

Her upbringing was a model of healthy living. The first of five children, “I grew up on my parent’s farm, living an outdoor life. We ate home-grown foods – we even made our own bread from our own grain. I remember fondly the nettle soup made out of plants we picked on the sunny spots early in the spring.”

As a student she walked an hour each way to her university classes. She hiked, she skied, she swam. Her health insurance reimbursed Mrs Palmer for 80% of the costs. “Neither the person responsible for the icy pavement nor the supermarket took any responsibility whatsoever.” “I have made up my mind never to fall again. I avoid going out when it’s icy, and am especially careful on escalators.”

December 2001

Karin Palmer, 63, has had no more fractures and her quality of life is back to normal – she and her husband took a walking holiday in the Slovenian Alps. “I was not affected by the disease, thank God.” Because there is cancer in her family, Mrs Palmer only takes a low dose of hormone replacement therapy. She feels that many osteoporosis patients are not treated properly because of “shortsighted cost calculations and lack of awareness by doctors.” Citing the situation of a patient with mild and therefore often undetected celiac disease, which impedes absorption of calcium in the digestive track, Mrs Palmer urges that osteoporosis prevention should not be limited to gynecologists but should become much more interdisciplinary.

- A large Austrian study, to assess the calcium and vitamin D status of the Austrian population and to establish normal values of bone mineral density (BMD), has been undertaken. The findings are due to be published in 2001.

# BELGIUM



## OVERVIEW

National population	10,000,000	
Population over 50	3,400,000	
Number of hip fractures in 1996	13,120	13.12 (per 10,000 population)
Number of hip fractures in 1998	No information available	
Number of hip fractures in 2000	No information available	
Total direct hospital costs of hip fractures	€140–180,000,000 (1996)	

### Recent major achievements

- Guidelines for the diagnosis and management of osteoporosis published by the Belgian Bone Club.
- Reimbursement for several anti-osteoporotic drugs (including bisphosphonates and selective oestrogen receptor modulators – SERMs) granted by health authorities.
- Belgian Society for Osteoporotic Patients – a patient-oriented osteoporosis society – founded.

### Important setbacks

- Bone densitometry is not reimbursed.
- Calcium and vitamin D are not reimbursed.
- Reimbursement for ERT (oestrogen replacement therapy) is only marginal.

### What action needs to be taken

- Identification and appropriate management of those at risk from osteoporotic fracture – including those with documented strong risk factors, such as glucocorticoid therapy or previous fractures, many of whom still do not receive appropriate advice.
- More research into the optimal timing and duration of therapy.
- State supported advertising directed at the Flemish-speaking community.
- Reimbursement to be made available for bone densitometry and calcium and vitamin D treatment.
- Improved reimbursement for oestrogen replacement therapy

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

Belgian authorities and, more specifically, the Ministry of Health and Social Affairs have not taken any significant moves to increase diagnosis of osteoporosis in Belgium.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?*

No such system has been established in Belgium.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

No information available.

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

No information available.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?*

The only action taken has been by the Belgian Bone Club, which obtained free television advertising.

*How has the budget changed since 1998?* No change – no budget.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

There have been no government-backed public health campaigns to promote increased calcium and vitamin D intake.

### Recommendation 5

#### ACCESS TO BONE DENSITOMETRY SYSTEMS

*Number of hip and spine DXA units per million population (as at beginning of 2000).*

20

*Average cost in € per DXA scan of the hip and spine (public and private health systems).*

€ 25 (ranges from free to € 100).

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).*

No reimbursement.

*Average waiting time for DXA scan (public and private health systems).*

No waiting list.

### Recommendation 6

#### PREVENTION/TREATMENT AND REIMBURSEMENT

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care? Guidelines were produced by the Belgian Bone Club and last updated in 1999.*

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

- Diagnosis: no reimbursement for bone densitometry. Reimbursement of some biochemical markers of bone turnover in particular conditions.
- Several effective medications (SERMs and bisphosphonates) are currently reimbursed (minimum level 75%).
- No reimbursement for calcium and vitamin D.
- Various levels of reimbursement for ERT.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?*

Yes, bisphosphonates and SERMs are only reimbursed if osteoporosis has been confirmed by either low BMD (DXA) or prevalent vertebral fracture.

#### Recommendation 7

#### THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS

*Has the government actively supported (financially or through public information) national patient and scientific societies?*

Not at all beyond the French-speaking community, which received television advertising.

*Do appropriate training programmes for healthcare professionals exist?*

The Belgian Bone Club organised training courses on bone densitometry for doctors and technicians and roundtable discussions on the appropriate use of biochemical markers of bone turnover.

#### Recommendation 8

#### RESEARCH

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

- Pre-clinical research and bone physiology studies which are funded by the Fund for Scientific Medical Research.
- A Thematic Network on Male Osteoporosis (NEMO) (see p41), bringing together multidisciplinary expertise from 10 European countries including Belgium, is being established.



“Don’t worry and take charge of your life.”

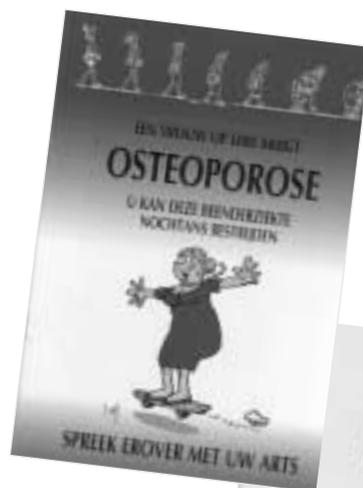
#### Patient story

June 1998

Family life is important to Simone Souris. She and her husband live on the ground floor of their home, a son and daughter-in-law on the first floor, and a second son and his wife on the second floor. Petite and dark haired, she is described by friends as “always smiling and seeing the positive side of life.” Mrs. Souris, 45, does not have osteoporosis, and doesn’t worry too much about getting it. If Mrs. Souris manages to avoid osteoporosis, part of the credit will go to her physician, who prescribed hormone replacement therapy for her hot flashes when she underwent an early menopause at the age of 36. Hormone replacement therapy is often given to treat osteoporosis, and early menopause is often an indicator that the disease will surface. Her outlook on life is positive and probably contributes to her resistance to the disease. “Don’t worry and take charge of your life,” she advises her friends.

December 2001

We have been unable to contact Simone Souris for an update.



Patient societies work to heighten public awareness of osteoporosis and its prevention.

# DENMARK



## OVERVIEW

National population	5,351,558	
Population over 50	1,806,510	
Number of hip fractures in 1998	9,470	17.70 (per 10,000 population)
Number of hip fractures in 2000	9,595	17.93 (per 10,000 population)
Total direct hospital costs of hip fractures	€47,975,000	

### Recent major achievements

- Consensus report on diagnosis and treatment of osteoporosis by the Danish Bone Society.
- Reimbursement regulations for osteoporosis drugs have been modified to include an additional number of risk factors, such as smoking and lack of exercise, beyond those already listed which include premature menopause, low body mass index, heredity, diseases and drugs causing secondary osteoporosis and previous fracture.

### Important setbacks

- There is no national strategy for dealing with the problem of osteoporosis.
- There is no general reimbursement of osteoporosis drugs for people with osteoporosis risk factors. Reimbursement is on a case by case basis. This is bureaucratic and time consuming to administer.

### What action needs to be taken

- Better access to DXA scanners across Denmark.
- Reimbursement of osteoporosis drugs for patients with accepted osteoporosis risk factors. Removal of the current bureaucratic reimbursement system.
- National action plan based on the consensus report.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

No, osteoporosis is not a priority among policy makers.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?*

A countrywide hip fracture registry is co-ordinated by orthopaedic surgeons.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

Not available from the current registers.

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

No information available.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?*

No.

*How has the budget changed since 1998?*

No change – no budget.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

The importance of calcium and vitamin D intake is mentioned in the consensus report, but there have been no specific education projects.

### Recommendation 5

#### ACCESS TO BONE DENSITOMETRY SYSTEMS

*Number of hip and spine DXA units per million population (as at beginning of 2000).*

7.4

*Average cost in € per DXA scan of the hip and spine (public and private health systems).*

Public: €45.

Private: €100.

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).*

Full reimbursement. But patients have to fulfil criteria relating to risk factors before a scan can be taken and there is a waiting list for DXA scans under the public health system.

*Average waiting time for DXA scan (public and private health systems).*

Public health system: average of 2 to 3 months.

Private health system: no information available.

The vast majority of the Danish population is treated in the public health system.

**Recommendation 6****PREVENTION/TREATMENT AND REIMBURSEMENT**

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care?*

Yes.

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

- **Diagnosis:** reimbursement for DXA scans if the patient fulfils risk factor criteria.
- **Drugs:** reimbursement on a case by case basis. The policy for reimbursement is determined by osteoporosis risk factors plus a lumbar or hip bone mineral density t score < -2.5 or z-score < -1 or a low energy fracture.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?*

Yes, patients have to fulfil criteria relating to risk factors (see above) and then are only reimbursed on a case by case basis.

**Recommendation 7****THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS**

*Has the government actively supported (financially or through public information) national patient and scientific societies?*

No.

*Do appropriate training programmes for healthcare professionals exist?*

No.

**Recommendation 8****RESEARCH**

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

- **Genetic determinants of peak bone mass and likelihood of fracture.**
- **Epidemiological study of falls and of osteoporosis which is a result of other conditions.**
- **Underlying causes of male osteoporosis.**

**Patient story**

**June 1998**

Kjell Fensmann likes nothing more than to fly fish for salmon and sea trout. He has no trouble when conditions call for a floating dry fly line. But when he changes reels to use a sinking line he complains that “it’s heavy work” which causes him back pain. Nevertheless, he continues to practise his sport, noting “I need to move and do something to strengthen my muscles. The exercise does me good.” Mr Fensmann, 53, a computer expert, has reason for complaining about his back. In 1992, he suffered “great pain” in his back for some eight months. He was shuttled from one specialist to another – no doctor could tell him what was wrong. Finally a neighbour, who is a doctor, suggested that Mr Fensmann see an osteoporosis specialist. An X-ray revealed that he had seven fractures on the spinal column. Mr Fensmann’s osteoporosis might be hereditary. He remembers that his mother had severe back pain, and thinks that perhaps she had osteoporosis although “in those days few people were diagnosed as having the disease. She was treated for her symptoms, not for her problem.”

**December 2001**

Although Kjell Fensmann, 56, has not had any new fractures, his back pain limits his activities. His bone density relative to his age has increased slightly to 65% from 60% in 1998. “Nobody will help you except yourself”, he says. Noting that osteoporosis affects men as well as women, he observes that osteoporosis is “not given any priority from a political point of view.” He and his wife try to teach their four children to eat healthily. Even though his back hurts he still tries to go fishing whenever he can.



# FINLAND



## OVERVIEW

National population	5,181,115	
Population over 50	1,773,517	
Number of hip fractures in 1998	7698	14.86 (per 10,000 population)
Number of hip fractures in 2000	No information available	
Total direct hospital costs of hip fractures	€150,000,000 (1998)	

### Recent major achievements

- In July 2000 the Finnish Medical Society, Duodecim, published national guidelines for the care of osteoporosis. Their aim is to improve the diagnosis of osteoporosis, establish a common practice for its prevention and treatment and to decrease the incidence of fractures, especially of the hip.
- Recent studies have shown that intake of vitamin D in Finland does not reach recommended levels, especially in winter. The Scientific Committee of the National Nutrition Council in Finland has recommended that milk and milk products be fortified with vitamin D.

### Important setbacks

- Osteoporosis patients in Finland receive a 50% subsidy for medication. The Finnish Osteoporosis Society has made several, so far unsuccessful, attempts to get this raised to 75%.
- Altogether there are 40 DXA units in Finland, there is no unit for public patients in the northern and eastern parts of the country.
- Vitamin D supplements for the elderly in nursing homes are recommended, but recent studies show that this is ignored by most nursing homes.

### What action needs to be taken

- Equal access to bone densitometry equipment throughout the country.
- Better prevention and treatment – identification and appropriate management of all those at risk from osteoporotic fracture.
- Osteoporosis should be adopted as a major healthcare target by government. Training programmes for healthcare professionals and more support for national patient societies should be funded.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

Unfortunately osteoporosis is not a priority in Finland despite the increasing number of fragility fractures.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?* Hip fracture rates are monitored by the Accident and Trauma Research Centre at the Urho Kaleva Kekkonen Institute for Health Promotion Research, Tampere, Finland. The data on hip fractures is calculated from the National Hospital Discharge Register.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

Total Number of Hip Fractures in Women and Men by Age (1998)		
Age	Incidence (Women)	Incidence (Men)
50–59	149	213
60–69	416	344
70–79	1544	618
80–89	2572	641
90	670	140

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

No information available.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?* The Finnish Rheumatism Association, the Finnish Back Society and the Finnish Osteoporosis Society have started working co-operatively as part of the Bone and Joint Decade on educational materials targeted at educators and volunteers working at the local level.

*How has the budget changed since 1998?* The Finnish Osteoporosis Society (FOS, created in 2000 in co-operation with the Finnish Back Association and the Finnish Rheumatism Association) is mainly funded by Finland's Slot Machine Association. The total budget for co-operation, FOS and its projects is approximately €340,000 – this is more than ten times 1998's budget.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

- In 1998 National Dietary Allowances were revised and the role of calcium and vitamin D in the prevention of osteoporosis was emphasised.
- The National Nutrition Board officially recommended from 2001 that all fluid milk products and all margarine, butter and margarine-like spreads should be fortified with vitamin D.
- There are no government-backed health campaigns to promote increased calcium intake (calcium intake in Finland is high).
- Two one- to two-year studies assessing the effect of vitamin D (and calcium) on bone in children are ongoing. In addition, there is a European study being co-ordinated at Helsinki

University (funded by the European Commission) in which Finland is a partner, to find the optimal dosage of vitamin D. If these studies produce new evidence new recommendations might emerge.

- In March 2000 the Finnish Osteoporosis Society established a three-year school project called *Rolling Bones*. The aim of the project is to motivate young people to adopt a healthy and active lifestyle that supports the growth of a strong skeleton. The target groups are teachers at comprehensive schools and children aged 9 to 15 years. The children are introduced to a "bone-friendly" lifestyle, including adequate calcium and vitamin D intake, regular exercise and the avoidance of smoking, excessive drinking of alcohol and dieting.
- The Finnish Osteoporosis Society and the Finnish Physiotherapist Association organised a two-day course on osteoporosis and physiotherapy for osteoporotic patients.

#### Recommendation 5

##### ACCESS TO BONE DENSITOMETRY SYSTEMS

*Number of hip and spine DXA units per million population (as at beginning of 2000).* 8

*Average cost in € per DXA scan of the hip and spine (public and private health systems).* Public: free (apart from a standard payment of approximately €25 for visiting a healthcare centre). Private: €80–115.

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).* Public: the national health system pays for a budgeted number of DXA scans. Patients must fulfil the criteria of the Finnish Medical Society guidelines. Private: doctors send patients for private bone mineral density measurement. KELA (the Social Insurance Institute of Finland) reimburses a percentage of the costs to the patient. The private health system plays a major role in the diagnosis and treatment of osteoporosis in Finland.

*Average waiting time for DXA scan (public and private health systems).* Public: 1 month. Private: 1 week.

#### Recommendation 6

##### PREVENTION/TREATMENT AND REIMBURSEMENT

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care?* • National guidelines by the Finnish Medical Society, Duodecim, were published in July 2000.

• At the local level, university hospitals and regional healthcare committees have produced their own guidelines based on the national guidelines.

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?* Public: following direct referral, scans, diagnosis and treatment are free to patients. Patients receive a 50% subsidy for the cost of medication. Private: patients get a refund of approximately €30 for the DXA scan cost and a 50% subsidy for medication.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?* Yes, for public patients they must fulfil the criteria for risk factors as set out in the national guidelines. Private patients need a doctor's referral for a scan.



#### Patient story

June 1998

Anna-Maija Nenonen's fight with osteoporosis started in 1988 when she fell and broke three ribs. Recovery took a long time. "Since the initial accident I get a new fracture almost every other year," she says. In 1991 she suffered a stroke, and had to retire from her job as a secondary school headteacher. In 1992, Anna-Maija Nenonen broke several bones in her right hand when her "beloved books" fell from the shelves. A short while later she broke other bones on the same hand when she shook hands with a friend. She then broke her left knee in 1995, and her left hand in 1997. She has lost 4cm in height, almost certainly due to undiagnosed vertebral fractures. Mrs Nenonen's situation reflects the fact that osteoporosis can strike anyone, including a person lacking all the "traditional" risk factors. There is no occurrence of osteoporosis in her close family. Mrs Nenonen, for example, has always been physically active and enjoys being in the sunlight. She eats normally, does not smoke, and has been relatively healthy for most of her life. In spite of her pain, Mrs Nenonen nevertheless takes long walks and loves to read – right now the biographies of Marie Curie and Vaclav Havel are on her bedside table. She is active in local politics as a member of the culture board in her local parliament. Her philosophy is that it is essential that you take responsibility – you cannot assume that anyone else will manage the care and treatment of your disease for you. Nevertheless, she feels "people are always willing to help if you ask."

December 2001

Mrs Nenonen, 69, has had no new fractures, although she still has pain in her hands and ankles and cannot walk for long distances. She continues her rich intellectual life, reading a wide variety of Scandinavian literature.

#### Recommendation 7

##### THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS

*Has the government actively supported (financially or through public information) national patient and scientific societies?*

In 2000 the Finnish Osteoporosis Society developed guidelines for physiotherapy for osteoporosis patients. The Ministry of Health supported this project with funding of €8350.

*Do appropriate training programmes for healthcare professionals exist? Training is extensive, but usually co-ordinated and sponsored by the private medical industry.*

#### Recommendation 8

##### RESEARCH

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

- Turku and Oulu universities are conducting basic research on bone metabolism, bone markers and the effects of various medicines on bone metabolism.
- Tampere University and the Urho Kaleva Kekkonen Institute for Health Promotion Research at Tampere are investigating the mechanical properties of bone and the effects of exercise on bone density.
- Kuopio Osteoporosis Study (OSTPRE) is an osteoporosis risk factor and prevention assessment which began in 1989 and includes the entire female population of Kuopio aged 47–56 in 1989 (14,220 individuals). This epidemiological study concentrates on osteoporosis and fracture risk factors and utilises repeat bone mineral density measurements and postal questionnaires to study the cohort.

# FRANCE



## OVERVIEW

National population	60,000,000	
Population over 50	10,000,000 women	
Number of hip fractures in 1998	55,000	9.17 (per 10,000 population)
Number of hip fractures in 2000	No information available	
Total direct hospital costs of hip fractures	€600,000,000 (1999)	

### Recent major achievements

- Three new drugs – two bisphosphonates (alendronate and risedronate) and a selective oestrogen receptor modulator (raloxifene) – for the prevention and treatment of osteoporosis have been approved.

### Important setbacks

- All three drugs are only reimbursed after a fracture.

### What action needs to be taken

- Recognition by health authorities of osteoporosis as an important disease.
- Reimbursement of DXA scan for the at risk population and reimbursement of the cost of drugs prescribed prior to fracture in patients with osteoporosis.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

Osteoporosis is viewed as a concern but not a priority. It has been included in the 10 diseases designated as deserving special attention in 2002 by the Ministry of Health.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?* No

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

Hip Fractures in Women by Age (per 10,000 population) 2000

Age	Incidence
50–54	0
55–59	11
60–64	16
65–69	22
70–74	44
75–79	82
80–84	131
85–89	295

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

No information available for vertebral fractures in women.

Vertebral Fractures in Men by Age (per 10,000 population) 2000

Age	Incidence
60–64	–
≥65	8

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?*

No specific funding has been dedicated by other partners, with the exception of the National Society for Rheumatology which ran a national symposium (November 2000) for physicians on osteoporosis – a “neglected disease”.

*How has the budget changed since 1998?*

No change – no budget.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

There have been no government-backed public health campaigns to promote increased calcium and vitamin D intake.

### Recommendation 5

#### ACCESS TO BONE DENSITOMETRY SYSTEMS

*Number of hip and spine DXA units per million population (as at beginning of 2000).*

17

*Average cost in € per DXA scan of the hip and spine (public and private health systems).*

€18–136.

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).*

Public: not reimbursed.

Private: €18–45.

*Average waiting time for DXA scan (public and private health systems).*

Public: up to 4 months.

Private: minimal.

### Recommendation 6

#### PREVENTION/TREATMENT AND REIMBURSEMENT

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care?*

There are no official guidelines at present. However, ANAES<sup>o</sup>, a government agency, is due to issue guidance shortly.

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

- DXA scans are not reimbursed under the public health system.
- Bisphosphonates and SERMs are only reimbursed after fracture.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?*

See above.

### Recommendation 7

#### THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS

*Has the government actively supported (financially or through public information) national patient and scientific societies?*

No

*Do appropriate training programmes for healthcare professionals exist?*

There is very little in the way of training programmes and nothing supported by the state.

### Recommendation 8

#### RESEARCH

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

- At government request, a pilot scheme in four regions of France, is due to start in 2002. It will investigate the benefit of diagnosing women over the age of 65, via a DXA scan, and their subsequent follow-up treatment over a three-year period. The scheme will evaluate the impact of treatment on fracture.
- A Thematic Network on Male Osteoporosis (NEMO) (see p41) is about to start in 10 EU countries, including France.

“I would say that the real decisions to be taken are more so on the administrative, legislative and ministerial side than on the medical side. A major public campaign is needed. Why not begin with a national petition demanding reimbursement for medical procedures, equipment, care and prevention?”

Marie-Claude Beaudeau  
Senator for Val-d'Oise, Osteoporosis Symposium 15 May 2001



#### Patient story

June 1998

Maryvonne was in her early 40s and had a very active and joyful life when osteoporosis struck her for the first time. She particularly enjoyed riding. One day she fell. “You expect to fall when you ride” she says, “but this time my wrist broke.” Within the next year Maryvonne broke bones at least three times. “I have lost confidence in myself,” she says. “I can no longer run in the street to catch a bus. I no longer feel young.” Instead she had to take care all the time. Since her fractures everything scares her and she “walks down the stairs like a fragile old lady.” Her mood changed: she feels “useless and depressed.”

Before getting the diagnosis of osteoporosis, Maryvonne had no idea her bone fragility could have anything to do with the hysterectomy she had 10 years earlier. “Nobody told me my ovaries had been removed.” The doctor started her on hormone replacement therapy. “I have recovered confidence in myself, but it will never be the same,” she says.

December 2001

Sadly Maryvonne died after a long fight with cancer. Her cancer was unrelated to her osteoporosis.

“I can no longer run in the street to catch a bus. I no longer feel young.”



Awareness campaign for World Osteoporosis Day 2001

# GERMANY



## OVERVIEW

National population	82,000,000	
Population over 50	28,000,000	
Number of hip fractures in 1998	130,000	15.85 (per 10,000 population)
Number of hip fractures in 2000	135,000	16.46 (per 10,000 population)
Total direct hospital costs of hip fractures	€1,462,240,000 (1996 costs, 1998 figures)	

### Recent major achievements

- Photographic exhibition (by the renowned photographer Oliviero Toscani) and campaign to raise awareness, by the Deutsche Grüne Kreuz (German Green Cross – DGK) and IOF. Free bone densitometry for the at risk population at the exhibition.
- Advertising the benefits of early diagnosis, osteoporosis risk assessment and treatment options, by the Kuratorium Knochengesundheit.
- The Bundesverband Osteoporose Selbsthilfegruppen (German Osteoporosis Patient Association) organised major events on World Osteoporosis Day.
- Bone and Joint Decade activities.

### Important setbacks

- There is only one department of clinical osteology in Germany.
- No extension of funding availability for bone mass measurement, i.e. for patients who have not yet suffered a fracture.

### What action needs to be taken

- Complete the development of certified guidelines for the diagnosis and treatment of osteoporosis.
- Implementation of these guidelines in the routine care of patients.
- More university level research – there is only one department of osteology.
- Develop more training courses for health professionals.
- Use the opportunities of the Bone and Joint Decade, in co-operation with IOF, to raise awareness in the general population and among health professionals.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

Osteoporosis is not a priority in Germany. However, the visibility of osteoporosis is improving, for example a press briefing was organised by the German Bone and Joint Decade on behalf of the Federal Ministry of Health; and a presentation on osteoporosis was made at a federal parliament committee hearing on Weltfrauentag (World Women's Day).

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?*

No such system has been established in Germany.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

No information available.

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

No information available.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?*

Mainly non-profit organisations including those with a special interest in people at risk of osteoporosis and osteoporosis patients such as Kuratorium Knochengesundheit, Bundesverband Osteoporose Selbsthilfegruppen and Deutsche Grüne Kreuz are involved. There is no support from health insurance companies or state organisations.

*How has the budget changed since 1998?*

There is no state budget for this aspect apart from through the German Bone and Joint Decade and patient societies.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

There is very limited emphasis placed on calcium and vitamin D education at present.

### Recommendation 5

#### ACCESS TO BONE DENSITOMETRY SYSTEMS

*Number of hip and spine DXA units per million population (as at beginning of 2000). 10*

*Average cost in € per DXA scan of the hip and spine (public and private health systems).*

Public: €45–55. Private: €45–80.

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).*

Public: €8–12. Scans are only reimbursed, if a patient has already sustained a fracture which may be related to osteoporosis.

Private: €15–25.

*Average waiting time for DXA scan (public and private health systems).*

Public: varies widely, average one to a few weeks.

Private: varies widely, average one to a few weeks.

### Recommendation 6

#### PREVENTION/TREATMENT AND REIMBURSEMENT

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care?*

- Various societies have reached consensus but there is no definite agreement.
- Evidence-based guidelines are being developed by the Dachverband (umbrella organisation of the German research societies), which are due to be published early 2002.

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

Diagnosis, treatment and care are reimbursed, if prescribed by a physician. Thus, in theory, all patients with osteoporosis have access to reimbursement. However, only a small proportion of physicians prescribe treatment adequately. This is due to the "budget system". For example, orthopaedic surgeons have a ceiling of €5–10 for drugs per three months for outpatient treatment. This limitation prevents physicians from prescribing freely and adequately.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?*

Yes, the patient must have suffered a fracture, before being diagnosed appropriately and there are extreme budgetary limits imposed on treatment.

### Recommendation 7

#### THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS

*Has the government actively supported (financially or through public information) national patient and scientific societies?*

- Once a society has been officially awarded charitable status the taxes levied on it and its fundraising are reduced.
- The Federal Ministry of Health offers support such as with the photographic exhibition and press briefings.

*Do appropriate training programmes for healthcare professionals exist?*

No.



#### Patient story

June 1998

Edmund Bonn, a baker, was forced to stop work in 1960, at the age of 24, when severe pain in his upper spine

made it impossible for him to bend over to pick up trays of dough. His spinal pain continued but he was never examined for osteoporosis. Doctors treated him instead for rheumatism and spinal deformity. In 1972, Mr Bonn broke a lumbar vertebra while helping a friend move his washing machine. The doctors said it was due to an accident or a weakness that he had from infancy. He broke a vertebra again in 1982, and still no one suspected osteoporosis. It was not until 1988 that doctors diagnosed osteoporosis.

Mr Bonn is frustrated that doctors did not diagnose his illness earlier. "I was in constant pain and had major problems in my professional life," he says. Mr Bonn has been helped by the German Osteoporosis Patients Society, where he is on the board. "The local support group has helped me a lot," he says. "My outlook on life is much better." Since joining the support group Edmund Bonn exercises regularly, and finds water gym particularly helpful. He has learned guidelines to reduce the risk of fracture. And since he has retired, his stress level is reduced.

December 2001

Edmund Bonn, 65, has had no further fractures and is preparing a short vacation to the Alps. He is sure that the exercises he does with his local self-help group helps to maintain his steady condition. He is pleased that osteoporosis is more often in the news. "You can see more about the disease in television or read about it in the newspapers," he says. "That will help us all."

### Recommendation 8

#### RESEARCH

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

- Research is underway at a small number of German universities (Berlin, Kiel, Bochum and Heidelberg) and the Bad Pyrmonter Research Institution. This limited number of scientific groups is involved in epidemiological work, looking at the role of vitamin D deficiency as a risk factor for falls, risk assessment, and the usefulness of ultrasound as a diagnostic tool.
- Privately funded institutions are also conducting research into risk assessment.

**"Only 17% of women (50 to 70 years) in Germany with a history of fragility fracture receive treatment."**

# GREECE



## OVERVIEW

National population	10,939,771 (2000)	
Population over 50	912,481 (≥65)	
Number of hip fractures in 1998	13,500	12.34 (per 10,000 population)
Number of hip fractures in 2000	No information available	
Total direct hospital costs of hip fractures	€44,550,000 (1998)	

### Recent major achievements

- The formation of an osteoporosis patient society, the Hellenic Society of Osteoporosis Patients Support.

### Important setbacks

- No government funding for information campaigns targeted at the general public, healthcare professionals and policy makers.
- Lack of statistical data to monitor the number of osteoporotic fractures, particularly of the hip, spine and wrist.

### What action needs to be taken

- Currently under analysis.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

No, osteoporosis is not considered a priority in Greece.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?*

No such system has been established in Greece.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

No information available.

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

No information available.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?*

No.

*How has the budget changed since 1998?*

No change – no budget.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

The Society of Osteoporosis Patients Support has organised lectures for health professionals and the general public, press releases, posters, leaflets, questionnaires and media events, to raise awareness about osteoporosis in general and the importance of calcium and vitamin D intake in particular.

### Recommendation 5

#### ACCESS TO BONE DENSITOMETRY SYSTEMS

*Number of hip and spine DXA units per million population (as at beginning of 2000).*

25.6

*Average cost in € per DXA scan of the hip and spine (public and private health systems).*

Request from the National Statistics Department unanswered at time of printing this report.

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).*

Request from the National Statistics Department unanswered at time of printing this report.

*Average waiting time for DXA scan (public and private health systems).*

Request from the National Statistics Department unanswered at time of printing this report.

### Recommendation 6

#### PREVENTION/TREATMENT AND REIMBURSEMENT

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care?*

No.

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

No official answer available.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?*

No official answer available.

**Recommendation 7****THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS**

*Has the government actively supported (financially or through public information) national patient and scientific societies?*  
No.

*Do appropriate training programmes for healthcare professionals exist?*

The Hellenic Institution for Osteoporosis (HELIOS) conducts an annual education programme for doctors, focusing on metabolic bone diseases.

**Recommendation 8****RESEARCH**

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

There are currently a number of research programmes throughout Europe in which Greece is participating.



“Now I realise that this disease can be cured and I already feel much better thanks to the treatment. I’m confident that I won’t be crippled in the future.”

**Patient story**

June 1998

Most people describe Basilios Karachalios as “positive and joyful”. However, since suffering from osteoporosis he has had to deal with physiological challenges of the disease as well as the psychological feelings of “invalidity”. Over the past decade, Mr Karachalios, 67, grandfather and retired primary school teacher, continually lost height and developed a worsening hunchback. Mr Karachalios was only diagnosed as having osteoporosis in the summer of 1997, following radiographs and measurement of spinal bone density. His treatment consisted of calcium and vitamin D, with exercises to reduce his hunchback and strengthen the muscles. “I had psychological problems when I was told that I suffered from osteoporosis,” he says. “Now I realise that this disease can be cured and I already feel much better thanks to the treatment. I’m confident that I won’t be crippled in the future.”

December 2001

Mr Karachalios 69, has gained some bone mineral density according to his age-matched score (76% today compared with 67% in 1997). He is satisfied with the treatment he receives and maintains his social activities.

Osteoporosis-related disability confines patients to more immobile days in bed than chronic obstructive pulmonary disease, stroke, myocardial infarction or breast cancer.

# IRELAND



## OVERVIEW

National population	4,500,000 (1996)	
Population over 50	1,485,000 (est.)	
Number of hip fractures in 1998	2777 ( $\geq 60$ )	6.17 (per 10,000 population)
Number of hip fractures in 2000	No information available	
Total direct hospital costs of hip fractures	€8,297,676 ( $\geq 60$ ) (1998)	

### Recent major achievements

- Video and workbook entitled *What is osteoporosis and how can you prevent it?* for use in schools produced by the Irish Osteoporosis Society, Women's Health Section of the Department of Health and Children and the Department of Education and Science.

### Important setbacks

- The private medical insurance agencies (VHI – Voluntary Health Insurance Agency and BUPA) do not pay for DXA scans for people at risk of osteoporosis.
- The government does not pay for DXA scans for medical card holders, i.e. low income individuals at risk of osteoporosis and for people >70 years of age with osteoporosis risk factors.

### What action needs to be taken

- Government and private medical insurance agencies need to pay for DXA scans for people with established risk factors for osteoporosis.
- More DXA machines need to be made available for medical card holders. Currently only 3 out of 24 DXA machines are for medical card holders.
- Additional education programmes in schools.
- Training for medical students and paramedics.
- Policy on the prevention of falls, particularly in people's own homes.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

Osteoporosis is not a priority in Ireland. Only 1 out of the 10 to 12 Health Boards has provided money for a hip and spine DXA unit and a peripheral DXA which measures bone density of the forearm. The peripheral DXA unit is used for screening people with osteoporosis risk factors to find out if they need to have, the more accurate and more expensive, hip and spine DXA scan. Most DXA units are privately funded. Only two Health Boards provide a small amount of funding to the Irish Osteoporosis Society.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?*

No.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

No information available.

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

No information available.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?*

There is co-operation between doctors from Northern Ireland and Ireland – this is funded by the pharmaceutical industry. The doctors meet together, exchange information and co-operate on guidelines for the prevention, diagnosis and treatment of osteoporosis.

*How has the budget changed since 1998?*

No change – no budget.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

The Irish Osteoporosis Society has organised educational activities, including seminars, with the help of the pharmaceutical industry, to educate the general public and healthcare professionals. Currently, there are no government policies for calcium and vitamin D education.

**Recommendation 5****ACCESS TO BONE DENSITOMETRY SYSTEMS**

*Number of hip and spine DXA units per million population (as at beginning of 2000).* 5.3

*Average cost in € per DXA scan of the hip and spine (public and private health systems).*

Average ranges from €76 to €102. Only 3 DXA machines are available for free scans for medical card holders.

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).* No reimbursement.

*Average waiting time for DXA scan (public and private health systems).* Up to 6 months.

**Recommendation 6****PREVENTION/TREATMENT AND REIMBURSEMENT**

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care? There are various complementary guidelines, which have been produced by the Irish Osteoporosis Society and also by a voluntary multidisciplinary group of healthcare osteoporosis experts.*

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

No, except for a few special cases.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?*

Yes, the patient must have a fracture before treatment is reimbursed or paid directly. The cost of drugs is free for lower income groups with a medical card. For all families who choose to join the scheme, drug costs totalling in excess of €53 per month are free.

**Recommendation 7****THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS**

*Has the government actively supported (financially or through public information) national patient and scientific societies?*

No.

*Do appropriate training programmes for healthcare professionals exist?*

No.



“I should have had a scan done when I first had pain”

**Patient story**

June 1998

Cynthia Moorehead loved riding, hunting and the outdoors. Since coming down with osteoporosis some seven years ago her life has changed considerably. After complaining of constant back pain, Mrs Moorehead was diagnosed as having osteoporosis. She was given hormone replacement therapy for a short while, then it was stopped. “In those days osteoporosis hadn’t really been acknowledged,” she says. “I should have been told to continue the hormone replacement therapy.” She advises other women in similar situations to have bone density scans. “I should have had a scan done when I first had pain,” she says. “In those days there were very limited facilities for diagnosing osteoporosis.” “I advise my daughters to have bone density scans,” Mrs Moorehead says. They don’t have a problem now, but osteoporosis could be in their genes.”

Today, Mrs Moorehead, 70, has “slowed down a lot.” She’s mostly housebound and can’t enjoy the long walks and gardening that used to keep her busy. She lives alone, and is grateful for a public service nurse “who keeps me out of a nursing home.”

December 2001

Cynthia Moorehead, 73, still lives on her own. She has had no further fractures. Her advice to women with osteoporosis? “Take that bloody HRT therapy,” she says.

**Recommendation 8****RESEARCH**

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

- Study on anorexia induced osteoporosis by Trinity Osteoporosis Centre, Dublin.
- Research projects and clinical trials analysing the effect of diet and exercise on bone density in different types of athletes including cyclists, runners, rowers, soccer players, gymnasts and Irish dancers.
- Project investigating the influence of exercise profiles on bone density in teenagers.



## OVERVIEW

National population	57,600,000 (est.)	
Population over 50	21,300,000 (est.)	
Number of hip fractures in 1998	75,000 (est.)	13.02 (per 10,000 population)
Number of hip fractures in 1999	78,478	13.62 (per 10,000 population)
Number of hip fractures in 2000	No information available	
Total direct hospital costs of hip fractures	€555,863,000 (1999)	

### Recent major achievements

- From December 1998, full reimbursement\* of alendronate for postmenopausal women with a history of fragility fractures of vertebrae or hip, and additionally from January 2001, full reimbursement of raloxifene and risedronate for the same group.
- From January 2000, full reimbursement of alendronate for men with a history of fragility fractures of vertebrae or hip, and full reimbursement of alendronate and risedronate for men and women treated for at least six months with 7.5 mg/day of prednisone (or equivalent dose of steroids) with a history of fragility fractures of vertebrae or hip.
- Recommendations and guidelines for general practitioners have been prepared by the largest association of GPs in Italy (FIMMG), Lega Italiana Osteoporosis (LIOS), a union of hospital doctors (ANAAO) and the Tribunale per i Diritti del Malato (TDM – “a court for patients’ rights”) and published in November 2001.

### Important setbacks

- In the absence of fractures, therapy for the primary prevention of osteoporosis (even if diagnosed according to WHO criteria) must be paid in full by the patient.

### What action needs to be taken

- Reimbursement of drug treatment for those diagnosed with osteoporosis according to WHO criteria, regardless of age and sex, and in the absence of previous fractures, including where osteoporosis is a secondary condition to chronic diseases.
- Resource planning (e.g. DXA equipment availability) for all regions of Italy. Currently provision is uneven – readily available in northern and central Italy but much less so in the south and the islands.
- Continuing medical education programmes for GPs covering osteoporosis.
- Establishment of an official medical speciality in metabolic bone diseases, for example a post-doctoral university degree recognised by the Ministry of Health.
- Government funding for information and prevention campaigns, in collaboration with patient associations and scientific societies, especially targeted at the young.

\* Patients receive the drugs free of charge at pharmacies, which are then reimbursed by the national health system.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

No, osteoporosis is not considered a priority.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?*

No such system has been established in Italy.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

Not available. It is possible to extract data from a national database which collects final diagnoses upon discharge from hospital. However, this data does not indicate the cause of the fracture (i.e. accident, major trauma or bone fragility).

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

As previous answer.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?* No.

*How has the budget changed since 1998?*

No dedicated budget – so no change.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

There have been no national policies by the Ministry of Health or Regional Health Departments, only local hospital initiatives and campaigns run by non-profit organisations such as a pilot education programme for pregnant women devised by LIOS and supported by IOF.

### Recommendation 5

#### ACCESS TO BONE DENSITOMETRY SYSTEMS

*Number of hip and spine DXA units per million population (as at beginning of 2000).* 10.5

*Average cost in € per DXA scan of the hip and spine (public and private health systems). Public: €78. Private: €156–260. (In Italy the usual practice is to make a DXA of the hip or the spine.)*

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems). Public: free to all over 65 years of age, those under 65 years pay €72. Private: there is no reimbursement; patients pay the full cost.*

*Average waiting time for DXA scan (public and private health systems). Public: 3–5 months. Private: 10 days (average).*

### Recommendation 6

#### PREVENTION/TREATMENT AND REIMBURSEMENT

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care? Evidence-based guidelines and consensus only exist at the local or regional level and are defined by local scientific societies. Recommendations and guidelines for general practitioners have been prepared by the largest association of GPs (FIMMG), LIOS, ANAAO and TDM – see recent major achievements.*

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

- In the public health system DXA scans are free to all those over 65 years, patients under 65 years receive 8% reimbursement.
- Lab tests, X-rays and specialist visits are paid in full directly by the national health system only for those over 65 years.
- From December 1998, full reimbursement of alendronate for postmenopausal women with a history of fragility fractures of vertebrae or hip.
- From January 2001, full reimbursement of raloxifene and risedronate for women with the same condition; full reimbursement for alendronate for men with a history of fragility fractures of vertebrae or hip; and full reimbursement of alendronate and risedronate for men and women treated for at least six months with 7.5 mg/day of prednisone (or equivalent dose of steroids) with a history of fragility fractures of vertebrae or hip.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment? Yes, see above.*

### Recommendation 7

#### THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS

*Has the government actively supported (financially or through public information) national patient and scientific societies? No.*

*Do appropriate training programmes for healthcare professionals exist? No Ministry of Health training programmes exist. Scientific societies concerned with bone metabolic diseases provide some training for specialists.*



*“I am always in pain and afraid of falling”*

#### Patient story

June 1998

Egle Pezzotta talks softly about the pain of osteoporosis. “I have continual pain,” the retired teacher from Milan says. “But the greatest pain is that I am unable to lift up my grandchild because of my back pain and fear that I will fall and crack some other vertebrae. I cannot do what an ordinary grandmother does.” In 1980, at the age of 45, Mrs Pezzotta underwent hysterectomy and oophorectomy due to fibromyomas and ovarian cysts. At that time she was not prescribed hormone replacement therapy. Four years later, she felt bone pain, and at her doctor’s recommendation, underwent a forearm bone density scan. This scan indicated that she had osteoporosis and she started treatment. Between 1986 and 1991 she broke both humerus and two lumbar vertebrae; she was forced to wear a rigid corset. Her pain worsened, and in 1995 “I had such violent hip pain that I was unable to move.” After the fractures, Mrs Pezzotta underwent various adjustments in her osteoporosis therapy, including vitamin D derivatives, bisphosphonates and oestrogen, but she couldn’t tolerate some of the drugs because they upset her stomach. In the last two years her bone mass has become stable, but she still suffers much pain, is always afraid of falling, and can only walk and do her household chores with great difficulty. She can’t remember the last time she had a good night’s sleep. “I have never been able to hold my grandchild in my arms,” she says. “She’s eight now, and she has learned to approach me very carefully because, as she says, ‘Nonna can break.’ ”

December 2001

Although Egle Pezzotta, 68, has had no new fractures, “I am always in pain and afraid of falling. I cannot even go to our weekend villa because it hurts too much to sit in a car.” She thinks that osteoporosis is still not known well enough. “The government doesn’t take osteoporosis into account, so it is not a health priority in Italy,” she notes. Her advice to other women? “Take care of your bones and learn how to prevent osteoporosis. Ask your doctor for more information. And be careful not to fall.” Her granddaughter Claudia is now 11. “Claudia looks after me as if I were a baby. She always says ‘Nonna, be careful.’ Sometimes Claudia encourages me: ‘Forza, Nonna,’ she says. ‘Let’s have a dance together because dancing is good for your bones.’ ”

### Recommendation 8

#### RESEARCH

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

- Multicentre research on modifiable determinants of peak bone mass and how these might be used to achieve higher peak bone mass in the population, and on assessing the cost/utility ratio of screening in older women, funded by the Ministry of Health, is ongoing.
- A Thematic Network on Male Osteoporosis (NEMO) (see p41) is about to start in 10 EU countries, including Italy.
- Several local studies, partially funded by universities, research institutes, the Ministry of Health and associations such as Telethon (a non-profit organisation which raises funds for medical research into genetic diseases), on all key areas of research identified as priorities in the 1998 report and on secondary osteoporoses (such as celiac disease and cystic fibrosis) are ongoing.

# LUXEMBOURG



## OVERVIEW

National population	440,000
Population over 50	137,500
Number of hip fractures in 1998	No information available
Number of hip fractures in 2000	No information available
Total direct hospital costs of hip fractures	No information available

### Recent major achievements

- The Association Luxembourg Ostéoporose (ASLO), an osteoporosis patient association, was founded in 1999.
- DXA densitometry equipment installed at one site. Until 2000 no DXA equipment was available in Luxembourg.
- Ministry of Health supported project to provide epidemiological data on osteoporosis launched.

### Important setbacks

- Osteoporosis is not included in the area of preventative medicine.
- No government funding for public information campaigns or for preventative measures.

### What action needs to be taken

- Once analysed, epidemiological data from the Ministry of Health supported study will allow Luxembourg to take decisions about osteoporosis policies in the future.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

No, osteoporosis is not currently a priority healthcare target in Luxembourg.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?*

Not yet – epidemiological data has started to be collected. As Luxembourg has just one DXA site, the country's data should be very accurate.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

No information available.

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

No information available.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?*

Association Luxembourgeoise d'Etude du Métabolisme Osseux et de l'Ostéoporose (ALEMO), the scientific osteoporosis association, and ASLO are working together to promote awareness about osteoporosis in the general population.

*How has the budget changed since 1998?*

No budget.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

Education about calcium and vitamin D intake is undertaken by ASLO via conferences, brochures and telephone help lines.

### Recommendation 5

#### ACCESS TO BONE DENSITOMETRY SYSTEMS

*Number of hip and spine DXA units per million population (as at beginning of 2000).*

1 (for the country's 440,000 population)

*Average cost in € per DXA scan of the hip and spine (public and private health systems).*

Public: €50.

Private: €70.

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).*

Public: actual cost reimbursed is 90% if the patient fulfils any of the 26 listed criteria for a DXA scan.

Private: approximately 90% of actual cost. No criteria for a DXA scan need to be fulfilled.

*Average waiting time for DXA scan (public and private health systems).*

From 1 to 4 weeks.

**Recommendation 6****PREVENTION/TREATMENT AND REIMBURSEMENT**

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care?*

No guidelines exist.

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

- Reimbursement for DXA is limited according to an indication list of 26 defined risk factors or diseases.
- Treatment and care costs are reimbursed up to 78% without restrictions. For example, bisphosphonates and SERMs are reimbursed prior to fracture and without DXA scan confirmation of osteoporosis.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?*

See above.

**Recommendation 7****THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS**

*Has the government actively supported (financially or through public information) national patient and scientific societies?* ASLO has preferred to function autonomously, funded by its membership and with non-governmental support. However, the government has agreed to make funding available with certain conditions, including for example approving ASLO's public information material. Up until now ASLO has not taken up the government's offer. Sufficient funding has been raised by other means – from membership fees, donations and industry support.

*Do appropriate training programmes for healthcare professionals exist?*

No co-ordinated programmes are available. Healthcare professionals receive training by attending meetings and conferences organised at individual speciality level. For example, the organisers of the monthly meetings of the society of physiotherapists invite a member of ALEMO to present the latest advances in osteoporosis therapy.

**Recommendation 8****RESEARCH**

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

No research is currently underway.



*“I now lead a normal life once again”*

**Patient story**

June 1998

Angèle M Schnadt-Tissen talks about her life as if it were a fairy-tale, with a happy beginning and end and a painful middle. “I was the fourth and last child born to a comfortable family where love enveloped me,” she says. Mrs Schnadt-Tissen, now 85, enjoyed a privileged life – good schools, then love and marriage to a handsome engineer. They moved to Brussels, “a pleasant city, where we made friends easily, like our neighbour Maurice Carême, who nourished me with his poetry.” They moved to Switzerland, where her husband Henri rose to the top of his profession. “But this warm and happy life with my two sons came to an abrupt end with the death of my husband,” she notes. She returned to Luxembourg in 1975.

In 1991 she broke her wrist in a fall, beginning a period of pain and frustration. Her wrist never healed properly. “I went for a cure every year,” Mrs. Schnadt-Tissen says. “Sometimes to Bad Ragaz, sometimes to Rheinfelden, sometimes in Italy, and the doctors always promised a miracle.” The miracle never arrived. Finally, in a spa in the Black Forest of Germany, she found a Canadian doctor who diagnosed her as having advanced osteoporosis. He recommended that she change doctors and consult a rheumatologist. “Little by little the pain has begun to disappear,” she says. “I now lead a normal life once again and have even travelled to Switzerland and Tunisia.”

December 2001

Now 88, Angèle Schnadt-Tissen has had no more fractures and takes a variety of osteoporosis medications. She lives independently and travels throughout Europe to visit family and friends.

# NETHERLANDS



## OVERVIEW

National population	16,061,921	
Population over 50	4,784,150	
Number of hip fractures in 1999	15,286 (≥55)	9.52 (per 10,000 population)
Number of hip fractures in 2000	No information available	
Total direct hospital costs of hip fractures	€180,374,800 (1999)	

### Recent major achievements

- Published guidelines for GPs for the diagnosis and treatment of osteoporosis.
- The Dutch Institute for Health Care Improvement, a non-profit organisation and the main body that produces guidelines in the Netherlands, is due to issue consensus guidelines in early 2002, in which general practitioners, specialists, physiotherapists and the Dutch osteoporosis patient society have participated.
- Large epidemiological studies of the elderly, with osteoporosis as a major focus, are ongoing in Rotterdam and Amsterdam. These studies analyse many areas including incidence of fractures, genetic causes of osteoporosis and related falls. This research is partially funded by a government agency.

### Important setbacks

- Although the Minister of Health adopted the advice of the Dutch Health Council on Osteoporosis in 1998, no related public action has yet been taken. The Dutch Health Council on Osteoporosis is a committee of external experts appointed by the Minister of Health to give advice on osteoporosis related policies.

### What action needs to be taken

- Those at risk of fracture need to be urgently identified.
- Pressure should be exerted at both national and European levels to recognise osteoporosis as a serious chronic disease.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

Osteoporosis is not a priority in any government recommendations regarding chronic diseases or diseases of the elderly in the Netherlands.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?*

There is a well-functioning national system of hospital admissions information through which hip fractures are registered. This records nearly all hip fractures and annual data are available upon request for a fee.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

This information can be obtained via the previously mentioned hospital admissions register of hip fractures for a fee.

For example:

Women: 20/10,000 (65–69 years), 280/10,000 (>85 years).

Men: 10/10,000 (65–69 years), 160/10,000 (>85 years).

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

An estimated incidence of vertebral fractures is also available from the hospital admissions register for a fee.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?*

Not aware of any action.

*How has the budget changed since 1998?*

There is no budget.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

There are no specific public campaigns to promote increased calcium or vitamin D intake. The average calcium intake of the Dutch population is one of the highest and a large placebo-controlled study on vitamin D intake in elderly people failed to show any effect on hip fracture risk. There is a public campaign (partly government financed) to promote exercise – this campaign includes information about osteoporosis.

### Recommendation 5

#### ACCESS TO BONE DENSITOMETRY SYSTEMS

*Number of hip and spine DXA units per million population (as at beginning of 2000).*

7.2

*Average cost in € per DXA scan of the hip and spine (public and private health systems).*

Varies widely, but estimated average cost €150. The Dutch population may choose between public or private health insurance however, both types of insured patients receive the same medical care. There are no private clinics.

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).*

Reimbursement is available within a budgeted system that varies between regions. The budgeted system is based on a set number of DXA scans which can be performed over a given time period. The budgeted number of DXA scans varies from region to region.

*Average waiting time for DXA scan (public and private health systems).*

Average 3 to 4 weeks.

#### Recommendation 6

### PREVENTION/TREATMENT AND REIMBURSEMENT

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care?*

Evidence-based guidelines for the identification and management of patients with osteoporosis have just been completed by the main body that produces guidelines, the Dutch Institute for Health Care Improvement; publication is expected early 2002.

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

Diagnosis and approved treatments are fully reimbursed with no particular restrictions.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?*

Diagnosis and approved treatments are fully reimbursed with no particular restrictions.

#### Recommendation 7

### THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS

*Has the government actively supported (financially or through public information) national patient and scientific societies?*

The government supports the osteoporosis patient society financially through a general programme for patient societies across a range of diseases. The level of financial support is based on the membership level of the patient society, the larger the patient society the larger the level of support.

*Do appropriate training programmes for healthcare professionals exist? No specific training programmes for health professionals exist. A national campaign, endorsed by the Dutch Society for Bone and Mineral Research, aimed at health professionals, is planned for the dissemination and implementation of the recently developed guidelines.*

#### Recommendation 8

### RESEARCH

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

- Research (partly government funded) in a number of areas identified in Recommendation 8 is being conducted via large epidemiological studies in Rotterdam and Amsterdam.
- As part of an international project, some data from the Rotterdam study, together with other large databases from



Photos courtesy of Hans and Ans van den Brink

### Patient story

The photos of Hans and Ans van den Brink's wedding in 1972 show that the happy bride and groom are the same height. Today Hans, 50, is a full head shorter than his wife, due to osteoporosis, which has severely reduced his skeletal mass. In 1982, during a holiday in Italy, he broke his hip when he stumbled while walking on an asphalt road. He has broken his ribs eight times. His osteoporosis was only diagnosed in 1990. Mr van den Brink has since taken a variety of medicines, but with little effect. Partly because he is in pain, and also because his wife suffers from multiple sclerosis, Mr van den Brink was forced to move to a smaller, easier to clean, home. But he was refused a new mortgage because he had osteoporosis, which is considered a chronic disease, by the bank. He had to stop working as a road construction worker and become a desk-bound clerk. He has been refused an increase in his life insurance policy. Mr van den Brink's two children, Jorgen, 23, and Nicole, 21, have also been diagnosed with osteoporosis and take medication. "The pain is the biggest handicap from osteoporosis," Mr van den Brink says. "It's there every minute of every day. My body is wasting away. A pain specialist prescribed morphine, but it makes me nauseous and sick. I'm worried about the future."

December 2001

Since 1998, Hans van den Brink, 54, has fractured a toe, a vertebra and a rib. "My quality of life has decreased," he says. My wife is confined to a wheelchair and I can't help her – I'm afraid of fracturing another bone." He tries to walk an hour and a half each day, but notes "my daily walks are far more difficult than three years ago." His son and daughter, now 27 and 25 respectively, had side effects from their osteoporosis medication, including nausea and, for the son, hair loss. "At the suggestion of their doctor they keep their osteoporosis a well-kept secret," Mr van den Brink says, "because they do not want to have the problems I had obtaining insurance and a mortgage." Mr and Mrs van den Brink are moving to an apartment which is designed to accommodate their disabilities. He is still unable to obtain insurance or a mortgage. "Greater emphasis should be placed on osteoporosis in men and children," he says. He advocates more exercise and healthier food for young people and advises people at risk to visit their general practitioner and ask for a bone density test. "Osteoporosis has brought our family together," he says. "In spite of the problems we nevertheless feel 'rich'."

countries around the world is being used to estimate 10-year fracture risk.

- The cost/utility ratio of fractures has been calculated for the Dutch population by the Dutch Health Research and Development Council. Some funding for this research has been provided by government organisations.

# PORTUGAL



## OVERVIEW

National population	10,318,000 (2001)	
Population over 50	1,533,800 (≥ 65, ≥ 50 not available)	
Number of hip fractures in 1998	8100	7.85 (per 10,000 population)
Number of hip fractures in 2000	8500	8.24 (per 10,000 population)
Total direct hospital costs of hip fractures	€51,321,300 (est. 2000)	

### Recent major achievements

- There are no recent achievements concerning the areas of diagnosis, prevention or information campaigns. However, access to diagnosis is unrestricted and bone mass measurements and treatments are reimbursed.

### Important setbacks

- The relevant authorities show no interest in osteoporosis (or any other musculoskeletal disease). The Bone and Joint Decade has not been officially endorsed by the government or health authorities.

### What action needs to be taken

- Implementation of diagnosis and treatment guidelines that effectively identify those at risk of fracture.
- Allocation of resources on the basis of greatest need.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

There is no evidence that osteoporosis is considered a priority.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?*

No such system has been established in Portugal.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

No information available.

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

No information available.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?*

No awareness that partners are working to fight osteoporosis.

*How has the budget changed since 1998? There was no budget in 1998 and in 2001 there is still no budget.*

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

There have been no government-backed projects. The education of health professionals is carried out mainly by the scientific society Sociedade Portuguesa das Doencas Osseas Metabolicas (SPODOM). Information campaigns aimed at the general public are run by patient associations although these tend to be poorly co-ordinated and executed.

### Recommendation 5

#### ACCESS TO BONE DENSITOMETRY SYSTEMS

*Number of hip and spine DXA units per million population (as at beginning of 2000).*

25 – only 7% of these units are in the public health system. However, almost all private centres provide access to patients from the public health system.

*Average cost in € per DXA scan of the hip and spine (public and private health systems).*

Public: €15. Less than 7% of DXA units are in the public system. The public system pays approximately €75 per scan to private centres for public patients.

Private: €100.

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).*

Public (including facilities in private centres): a maximum charge of €15 is levied. However, a significant proportion of patients, due to low income or chronic disease (other than osteoporosis), pay nothing. Retired people with a pension below the minimum national wage pay nothing for diagnostic tests and pay 15% of medication costs.

Private: in Portugal almost everyone uses the public system for diagnostic tests, either directly, or for private patients, by referral by a public doctor (allowing the costs of scans made at private centres to be reimbursed to the patient by the public sector).

Private patients choosing not to take up this option pay the full price of the scan.

*Average waiting time for DXA scan (public and private health systems).*

Public: 1–2 months.

Private: 1 week.

**Recommendation 6****PREVENTION/TREATMENT AND REIMBURSEMENT**

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care?*

Guidelines on diagnosis have been produced by the College of Rheumatology of the Portuguese Medical Association, but these have not been officially adopted.

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

Yes, but only as part of the general policy of reimbursement, i.e. this is not particular to osteoporosis.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?*

No limiting criteria.

**Recommendation 7****THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS**

*Has the government actively supported (financially or through public information) national patient and scientific societies?*

No.

*Do appropriate training programmes for healthcare professionals exist?*

No programmes exist.

**Recommendation 8****RESEARCH**

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

There are no ongoing research programmes supported by the authorities.



“When I think about how my mother died after a hip fracture I get really worried”

**Patient story**

June 1998

In retrospect it's easy to see why António Matos was likely to get osteoporosis. Mr Matos, a retired economist, is a walking catalogue of risk factors. He lives a sedentary life. He eats few foods containing calcium. He smokes. A diabetic for the past 35 years, he has been on insulin since 1987, and there is a possibility that this too contributed to his osteoporosis. But most important was that Mr Matos's mother died following a hip fracture – there is a strong genetic susceptibility to the disease. He was diagnosed with osteoporosis three years ago. “I had a cold and coughed a lot,” he remembers. “I smoke and even common colds are difficult to handle. After a particularly violent coughing spell I felt a sharp pain in my middle back. The pain got worse every day and I couldn't perform my daily tasks.” Mr Matos's family doctor requested an X-ray and detected two vertebral fractures in the dorsal spine. “The doctors thought I had some other disease, but after many, many examinations they finally agreed that the only possible diagnosis was osteoporosis.” He has broken his spine three times.

In a sense, Mr Matos is lucky. He keeps busy, has a comfortable lifestyle and the support of his family and friends. But he has always been plagued by health problems. He suffers from hypertension and takes medication for the condition. For almost 30 years he used to smoke about 40 cigarettes a day, but has cut down since getting arteriosclerosis 15 years ago, which led to a femoral bypass operation. “I now smoke about 10 a day,” he says. “Doctors are always telling me to quit. Now they say it's even bad for my bones.” “When I think about how my mother died after a hip fracture I get really worried. I try to avoid falls and have to be doubly careful because I don't see too well due to my cataracts.”

December 2001

Mr Matos celebrates his 79th birthday on the day this document is launched. He has not had any further fractures, but was admitted to the intensive care unit for complications relating to his other diseases – diabetes, high blood pressure and arteriosclerosis. Mr Matos frequently has back pain. He advises people who might be of risk of osteoporosis to “change their bad habits before it is too late. Look what my bad habits, like smoking, did to me. I only stopped smoking after they put me in intensive care.”

# SPAIN



## OVERVIEW

National population	39,852,651	
Population over 50	7,283,000 women (1998)	
Number of hip fractures in 1995	30,460	7.6 (per 10,000 population)
Number of hip fractures in 1998	No information available	
Number of hip fractures in 2000	No information available	
Total direct hospital costs of hip fractures	€220,000,000 (1995)	

### Recent major achievements

- Improved availability of bone mineral density measurement.
- Better drug treatments.

### Important setbacks

- Less public money for bone research.
- Fewer metabolic bone units in general hospitals.

### What action needs to be taken

- Identification and appropriate management of all those at risk from osteoporotic fracture – including those with well documented strong risk factors, such as glucocorticoid therapy or previous fractures, many of whom still do not receive appropriate advice.
- More research into the optimal timing and duration of therapy.
- Stimulate and support patient-oriented groups at a national and local level.
- Osteoporosis training for general practitioners and orthopaedic surgeons.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

Some state support is provided for information campaigns and for scientific meetings and dissemination of scientific reports, but there are still no facilities for early diagnosis or prevention for the general public.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?*

Not yet, only individual epidemiological studies at local and provincial levels by individual researchers.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

Only data available is from the multinational Mediterranean Osteoporosis Study (MEDOS) which includes two centres in Spain, Madrid and Seville.

*Hip Fractures in Women by Age (per 10,000 population) 1990 (data from France, Greece, Italy, Portugal, Spain and Turkey combined)*

Age	Incidence
50–54	1.10
55–59	2.10
60–64	4.70
65–69	10.00
70–74	17.00
75–79	38.00
≥80	107.50

*Hip Fractures in Men by Age (per 10,000 population) 1990 (data from France, Greece, Italy, Portugal, Spain and Turkey combined)*

Age	Incidence
50–54	1.00
55–59	1.60
60–64	3.40
65–69	5.50
70–74	8.10
75–79	19.00
≥80	53.40

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

Only data available is from the multinational European Vertebral Osteoporosis Study (EVOS) which included five cities in Spain.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?*

Possibly, but through projects studying ageing, rather than osteoporosis specifically.

*How has the budget changed since 1998?*

No information available.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

Fundación Hispana de Osteoporosis y Enfermedades Metabólicas Oseas (FHOEMO) and municipal and provincial health agencies run some projects with a strong nutrition component aimed at improving quality of life.

**Recommendation 5****ACCESS TO BONE DENSITOMETRY SYSTEMS**

*Number of hip and spine DXA units per million population (as at beginning of 2000).*

8

*Average cost in € per DXA scan of the hip and spine (public and private health systems).*

€90.15 (private health system).

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).*

Public: free when referred by a specialist.

Private: health insurance covers between 80–100% of actual costs.

*Average waiting time for DXA scan (public and private health systems).*

Public: 6–12 months.

**Recommendation 6****PREVENTION/TREATMENT AND REIMBURSEMENT**

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care?*

There are several guidelines recommended by scientific societies, but general practitioners do not follow a standardised osteoporosis management procedure.

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

Yes, within the public health system.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?*

The usual limiting criteria prevail for medicines prescribed within the public health system. Retirees receive 100% of costs, others 40%.

**Recommendation 7****THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS**

*Has the government actively supported (financially or through public information) national patient and scientific societies?*

No change since 1998 – no budget.

*Do appropriate training programmes for healthcare professionals exist?*

Scientific societies, such as rheumatology and endocrinology, have developed specific training courses. The Sociedad Espanola de Investigaciones Oseas y Metabolismo Mineral (SEIOMM) in partnership with the International Society of Clinical Densitometry (ISCD) and FHOEMO in partnership with IOF run periodic training courses for general practitioners.

**Patient story**

June 1998

For more years than she wishes to remember, Carmen Sanchez suffered back pain. She was unable to

perform her daily tasks. She shrunk 8cm. Mrs Sanchez suffered for five years before a doctor performed a bone density test, which indicated that she had osteoporosis. Her illness almost certainly results from a hysterectomy with double ovariectomy when she was 35 years old; she did not receive hormone replacement therapy for this surgical early menopause.

“Osteoporosis no longer disrupts my daily life,” Mrs Sanchez says. She can once again carry heavy packages and wash the floor and cook and attributes her improved condition to appropriate treatment, exercise and diet.

December 2001

Since 1998, Carmen Sanchez suffered a wrist fracture and a crushed vertebra; nevertheless, a new treatment has helped her to “feel useful again.” As president of the Spanish Osteoporosis Patients Society (AFHOEMO), Mrs Sanchez gives numerous media interviews with the message that “we women should take responsibility for our bone health and fight osteoporosis to regain control of our lives.” Mrs Sanchez notes that while public awareness about osteoporosis has improved, “government policies haven’t changed very much and we have to make government leaders aware of the need for urgent action.” She urges all women who have bone pain to get a bone density scan. “My quality of life improved once doctors realised I had osteoporosis and we could treat it properly,” she says.

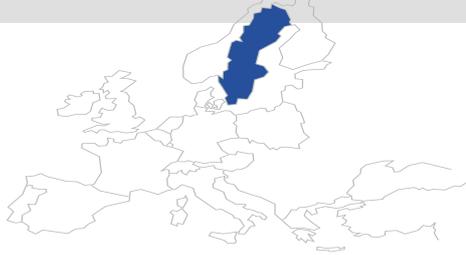
**Recommendation 8****RESEARCH**

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

- There are several private and public-supported clinical trials devoted to epidemiology, genetics and to new drug development. Some of the latter are involved in multicentre, multinational trials.
- A Thematic Network on Male Osteoporosis (NEMO) (see p41) is about to start in 10 EU countries, including Spain.

Only 18% of osteoporotic patients are diagnosed by DXA in Spain. 72% of the primary care physicians don't have access to this diagnostic test.

# SWEDEN



## OVERVIEW

National population	8,900,000	
Population over 50	3,200,000	
Number of hip fractures in 1998	17,926	20.14 (per 10,000 population)
Number of hip fractures in 2000	No information available	
Total direct hospital costs of hip fractures	€300,000,000 (1998)	

### Recent major achievements

- New guidelines for the treatment of osteoporosis, prepared by the Medical Product Agency (MPA), a government agency primarily concerned with approving drugs, issued to all doctors (2001).
- The Swedish Osteoporosis Society has revised and published updated guidelines for diagnosis and treatment of osteoporosis with up-to-date background information (1999).
- The National Institute of Public Health, a government agency, has launched a campaign for increasing physical activity among the population "Sweden on the Move". The programme includes benefits for bones and fracture prevention.
- "Health for the Elderly", a two-year campaign by the National Board of Health and Welfare (NBHW) (the government authority responsible for licensing, policy implementation and quality assessment) in 21 communities, included information on primary fracture prevention.
- A number of new osteoporosis units in local hospitals have been established.

### Important setbacks

- There are no national (NBHW) guidelines for osteoporosis. On the contrary, some investigations and decisions undertaken by the NBHW on drug treatment, disability and functional impairment counteract some of the aims of current guidelines.
- The National Health Care Committee (a temporary Parliamentary Committee) has, in a recent report, not designated osteoporosis as a national healthcare priority.

### What action needs to be taken

- Educational programmes on prevention directly targeting primary care professionals and social care professionals.
- Educational programmes directed towards health policy makers and governmental officials.
- Programmes increasing the hours of physical activity/education in the public school system, including information on the benefits to bones and joints (study ongoing).
- Awareness-raising campaigns on osteoporosis and the prevention of fractures.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

At neither government or regional health authority level has osteoporosis been designated a priority healthcare issue. However, through the Swedish Council on Technology Assessment in Health Care, a government agency, two projects have been initiated. The first is an evaluation of the scientific foundation for present methods for prevention, diagnosis and treatment of osteoporosis. The second looks at the risks and benefits of oestrogen treatment. Recently the NBHW has published state-of-the-art reports on osteoporosis and on hip fracture treatment and the MPA guidelines have been issued to all doctors.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?*

No such system has been established in Sweden.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

No information available.

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*  
Not information available.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?*  
No action has been taken in this area.

*How has the budget changed since 1998?*  
There is no budget.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

There are no government initiated projects. However, there are numerous projects involving joint funding, run by local health authorities, for example the two-year project on Health for the Elderly run by the NBHW in 21 communities.

### Recommendation 5

#### ACCESS TO BONE DENSITOMETRY SYSTEMS

*Number of hip and spine DXA units per million population (as at beginning of 2000).* 4.8

Average cost in € per DXA scan of the hip and spine (public and private health systems). €70.

Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).

Healthcare is mainly public, funded by taxation. Patients pay part of the fee, the level of which is determined by the local health authority.

Average waiting time for DXA scan (public and private health systems).

Public: varies widely from 2 weeks to 3 months.

Private: no information available.

### Recommendation 6

#### PREVENTION/TREATMENT AND REIMBURSEMENT

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care?*

Yes – MPA guidelines and Swedish Osteoporosis Society and Swedish Council on Technical Assessment in Health Care reports. Local guidelines are usually based on these.

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?*

- Diagnosis: costs are usually covered except for a patient fee which is set by local health authorities. A common fee is €21 for the first consultation (lower for follow-ups).
- Treatment: the cost of drugs is reimbursed but there is a patient fee (a maximum charge per annum applies). National Drug Insurance, financed by the national budget, covers pharmaceuticals prescribed by doctors. Through this, an individual patient's costs for pharmaceuticals in any given year, above a maximum fixed amount or 'ceiling', are covered.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?*

There are no limiting criteria for reimbursement but doctors are encouraged to refer to the guidelines mentioned earlier. Patients do not have to prove they have osteoporosis in order to receive reimbursement for treatment. In private clinics, without reimbursement deals with the national healthcare system, the patient pays the full cost of bone mass measurements.

### Recommendation 7

#### THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS

*Has the government actively supported (financially or through public information) national patient and scientific societies?*

To date, the NBHW, which awards funding, has denied the Swedish Osteoporosis Patients' Society a grant because it does not consider that osteoporosis causes major, long lasting functional impairment but rather that it causes a predisposition for impairment.

*Do appropriate training programmes for healthcare professionals exist?*

- Osteoporosis is included in the curriculum for medical and nursing students at most teaching institutions.
- Other training programmes are run through the Swedish Osteoporosis Society, often with sponsorship from the



and courtesy of Inger Lundegaardh

Photos taken by Lennart Lundegårdh

#### Patient story

June 1998

A series of photos of Inger Lundegaardh show how osteoporosis transformed the body of a beautiful young woman of 20 into a hunched woman of 59. Mrs Lundegaardh lived a typical active Swedish life – she taught secondary school, enjoyed gardening and spent summer holidays on an island in the Baltic Sea.

“Osteoporosis interfered with my life 11 years ago,” she says. “After playing tennis for an hour my arm started to ache. I did not go to the doctor, thinking that it was a small problem and that the arm would heal by itself. Eventually I had an X-ray which showed that the arm had been broken.” “The real problems started soon after.” Within six months Mrs Lundegaardh had broken her thigh bone three times. The first fracture occurred after cycling and the second after walking. The third fracture was a direct result of an “unskilful” operation, after her “skeleton had already become very, very brittle.” Her husband, Lennart, who was then science editor of *Svenska Dagbladet*, a leading daily newspaper, arranged a bone density exam, which led to the diagnosis of osteoporosis, long after the first fracture. Six years ago surgeons inserted an artificial hip. She has lost 22 cm in height. “My daily life has changed completely,” Mrs Lundegaardh says. “I now walk with two canes. I can't bend down and I'm constantly in pain. I cannot carry things and therefore cannot go shopping. I miss my active life, very, very much.” “The worst thing about osteoporosis is that I have lost so much height that when I go to a concert or to a restaurant I have to sit on a special cushion.”

December 2001

In 1999, Mrs Lundegaardh fell at home. “I stayed in bed for one night and half a day pretending that it would be okay. Finally the ambulance came and I was taken to hospital. The doctors replaced my artificial hip and also operated on my other leg.” Mrs Lundegaardh, 63, and her husband go ‘stick walking’ three times a week. “It means huffing and puffing but my breathing improves from the exercise.” While acknowledging that awareness of osteoporosis has improved, she feels much more needs to be done. “In a town in the southern part of Sweden the head of the orthopedic department was asked why he never used the bone density scanner. He replied ‘we haven't had time or resources to use it.’ I wonder how many patients he and his colleagues will send into great pain and poor quality of life.” Mrs Lundegaardh, member of the board of the Swedish Osteoporosis Patients' Society has this advice for other women: “If you think you need a bone density test, don't leave your doctor's office until he gives you what you demand.”

pharmaceutical industry. Courses on osteoporosis have also been jointly arranged through specialist societies for primary care physicians, geriatricians and orthopaedic surgeons.

### Recommendation 8

#### RESEARCH

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.*

There are numerous research projects being conducted nationwide, for example on male osteoporosis and on physical activity from childhood to young adulthood.

# UNITED KINGDOM



## OVERVIEW

National population	60,000,000	
Population over 50	20,000,000	
Number of hip fractures in 1998	70,000 (est.)	11.67 (per 10,000 population)
Number of hip fractures in 1999	86,408	14.40 (per 10,000 population)
Number of hip fractures in 2000	No information available	
Total direct hospital costs of hip fractures	€847,284,600 (1999)	

### Recent major achievements

- A National Service Framework (NSF) on older people which includes osteoporosis and prevention of falls has been introduced. NSFs have been introduced by the Labour government as part of its public health system reforms and modernisation. NSFs set national standards for the care of diseases which are given a high political priority. To date, there are NSFs on mental health, heart disease, cancer and older people.
- Primary care strategy for falls and osteoporosis developed by the National Osteoporosis Society (NOS), UK.
- Royal College of Physicians (RCP) guidelines first published in 1999, updated in 2000.

### Important setbacks

- A NSF dedicated to osteoporosis has not been introduced.
- Bone densitometry resources are still patchy nationwide and many physicians do not have access to DXA measurements.

### What action needs to be taken

- Identification and appropriate management of all those at risk from osteoporotic fracture – including those with well documented strong risk factors, such as glucocorticoid therapy or previous fracture, many of whom still do not receive appropriate advice.
- Development of better tools for risk assessment.
- More research into the optimal timing and duration of therapy.
- The impact of osteoporosis on employees, employers and healthcare systems needs to be assessed.

### Recommendation 1

#### IS OSTEOPOROSIS A PRIORITY?

- The UK government NSF on older people refers to osteoporosis and falls, but as a priority osteoporosis still ranks well below mental health, heart disease and cancer. Since osteoporosis and falls are included, though they account for only a relatively small proportion of the NSF on older people, authorities may be less likely to create a NSF dedicated to osteoporosis in the future.
- The National Institute of Clinical Excellence (NICE), established by the Labour government as part of the clinical governance agenda, plans to address the effectiveness of osteoporosis treatments. NICE, which assesses technologies and treatments and issues national guidelines, has so far covered subjects such as Viagra, beta-interferon for multiple sclerosis and treatment for Alzheimer's. The inclusion of osteoporosis treatment could be a sign that the disease is regarded as a national priority, but it could also be seen as an attempt to limit prescribing in an area in which a huge population is potentially at risk.

### Recommendation 2

#### FRAGILITY FRACTURE STATISTICS

*Has a co-ordinated system for the monitoring of fragility fracture rates, with particular reference to secular trends, been set up at a national level?* No such system has been established in the UK.

*Age/sex specific incidence rates for hip fracture within 5-year age bands above 50 years (per 10,000 population).*

No information available.

*Age/sex specific prevalence rates for vertebral fractures within 5-year age bands above 50 years (per 10,000 population).*

No information available.

### Recommendation 3

#### CO-OPERATION AND FUNDING

*Are partners helping to fight osteoporosis?* Not aware of any action to this effect other than funding by the European Commission of the Bone and Joint Decade Health Strategies project (see p40) which includes osteoporosis and the UK.

*How has the budget changed since 1998?*

Not aware of any national budget.

### Recommendation 4

#### CALCIUM AND VITAMIN D EDUCATION

- There have been no government-backed public health campaigns to promote increased calcium and vitamin D intake.
- There are at least two three-year studies ongoing in the UK which are investigating the effects of vitamin D alone, calcium alone and vitamin D and calcium combined in preventing hip fractures in people aged 70 years and above. If these produce positive results formal public health recommendations might emerge.

**Recommendation 5****ACCESS TO BONE DENSITOMETRY SYSTEMS**

*Number of hip and spine DXA units per million population (as at beginning of 2000).* 4.2

*Average cost in € per DXA scan of the hip and spine (public and private health systems).* Public: €87. Private: €160–242.

*Actual cost reimbursed or paid directly per DXA scan of the hip and spine (public and private health systems).* Public: the National Health Service pays directly for a budgeted number of DXA scans. Scans are only permitted if the patient fulfils criteria, usually according to local guidelines, which are generally based on the RCP guidelines.

Private: under most insurance schemes patients are reimbursed for the first bone measurements regardless of the indication. However, BUPA (one of the major insurance companies) does have a list of indications similar to those issued by the RCP, although it is not entirely consistent about using them. Most insurance companies reimburse follow-up measurements – again, BUPA is somewhat inconsistent in its practice here.

*Average waiting time for DXA scan (public and private health systems).* Public: varies widely, average 2–3 months. Private: 2–3 weeks.

**Recommendation 6****PREVENTION/TREATMENT AND REIMBURSEMENT**

*Do evidence-based guidelines or consensus exist on diagnosis, treatment and care?* At the local level numerous guidelines have been produced in the last few years, usually based on the national guidelines produced by the RCP. At national level there are the RCP guidelines and update.

*Is there a policy for reimbursement or for directly paying for diagnosis, treatment and care?* Public: yes, budgeted services include both direct referral for a scan and outpatient consultations which include diagnosis, treatment and care. Currently Health Authorities, and in the near future Primary Care Trusts (PCTs), allocate a certain amount of money for diagnosis and consultations. The specific costs of medical treatment are not budgeted separately but make up an unspecified part of the total drugs budget. Health Authorities and PCTs may, however, refuse a treatment if they think it is too expensive. Patients pay prescription charges, which are not reimbursed, for their drugs. Certain categories are exempt from prescription charges, for example the chronically ill and elderly. Private: patients are reimbursed for their consultation and scan. They pay for their drug treatment in the same way as NHS patients, via prescription charges, which are not reimbursed. Certain categories are exempt from prescription charges, for example the chronically ill and elderly.

*Are there limiting criteria for reimbursement or for directly paying the costs of treatment?* Public and private: all patients pay via prescription charges, which are the same regardless of the price of the drug. Certain categories are exempt from prescription charges, for example the chronically ill and elderly.

**Patient story**

June 1998

As a teenager, Anna Peckham went through a generation of pain. At 15 Anna was almost six feet tall and weighed 68kg. Preparing for the summer holidays, she began a diet that was to mark the beginning of her struggle with anorexia. Her periods stopped

completely and over the next few years her weight tumbled as low as 37kg. Treatment, including several months in a child and adolescent psychiatric unit, failed to help. Finally, at the age of 19 Anna regained weight and was able to begin college. It was a new start for Anna. During her part-time work in a residential home she first noticed backache, but put it down to her work lifting patients. One morning though, while getting ready for college, "I felt this excruciating pain; pain that I have never felt before or since. It shot right down my back and I fell to the floor. I screamed to my dad that I needed help, then crawled along the landing back to bed. It was terrifying because I couldn't stand up." Anna's doctor diagnosed a slipped disc and prescribed bed rest. It was when Anna started walking again that her mother noticed she was no longer taller than her sisters. The effect of Anna's anorexia became apparent; she had suffered vertebral fractures and lost 5cm in height. A bone density scan confirmed osteoporosis. "It was a horrendous time for me, I realised I had wasted part of my life, and that if I didn't want the rest of it to pass me by, I had to do something." Since her diagnosis, Anna has been prescribed high-dose contraceptive pills to boost her oestrogen levels, she exercises regularly and eats a calcium-rich diet, all of which help to increase her bone density. Anna has gained a place at medical school and is currently working in a psychiatric unit.

December 2001

Anna Peckham married in 1999; her surname is now Richman. Now 31, she no longer takes high-dose oral contraceptives, but continues with calcium and vitamin D; she has had no additional fractures and her bone density has also improved over the last 10 years. "My life is not restricted by osteoporosis," she says. Her advice to anyone with an eating disorder or strict diet: "Think about how osteoporosis can affect you and your body shape. Most people's weight fluctuates, but once you have lost five cm in height you will never get it back!"

**Recommendation 7****THE NGO SECTOR AND TRAINING HEALTHCARE PROFESSIONALS**

*Has the government actively supported (financially or through public information) national patient and scientific societies?*

There is no budget. Government support is limited to occasional verbal encouragement.

*Do appropriate training programmes for healthcare*

*professionals exist?* • There has been no change since 1998. The Bone and Tooth Society (scientific society) and the Royal College of Physicians intend to perform an audit of training for specialist registrars in rheumatology, endocrinology and metabolic medicine. Osteoporosis will be central to this audit.

• IOF conducts training programmes in partnership with national societies. Training programmes, focusing on quality delivery of bone measurement services, osteoporosis treatment guidelines for orthopaedic surgeons to prevent new fragility fractures and improved recognition and reporting of vertebral fractures by radiologists are being planned and implemented.

**Recommendation 8****RESEARCH**

*Specify major research which is underway especially involving the areas outlined in Recommendation 8.* • Government-funded research through Health Technology Assessment (HTA) is assessing the cost/utility ratio of screening older women.

• A Thematic Network on Male Osteoporosis (NEMO) (see p41) is bringing together multidisciplinary expertise from 10 European countries including the UK, is being established.

# Overview and analysis of national audits

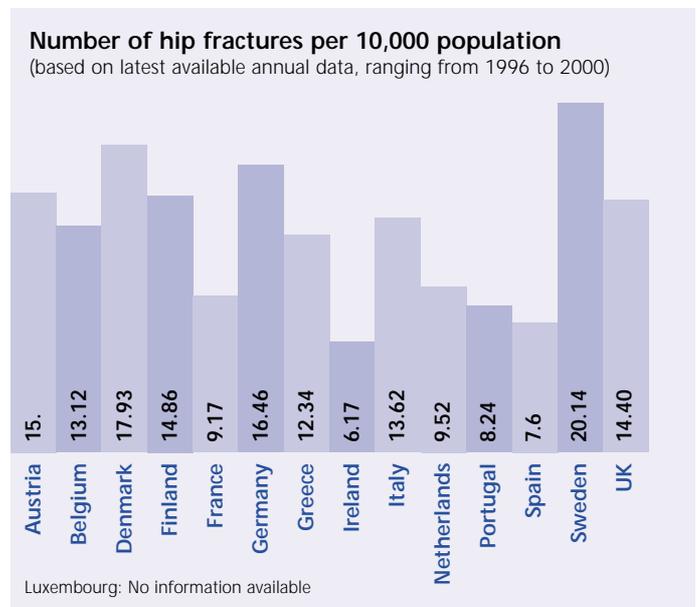
This audit report analyses the implementation, in each of the 15 European Community member states, of the eight recommendations outlined in the 1998 Report on osteoporosis in the European Community: Action for prevention (a European Commission publication). Through the audits an up-to-date picture of provision for osteoporosis and recent progress in each of the 15 member states is presented. While in some countries promising initiatives have been reported we will see that in many countries little has improved over the last three years. Therefore, the European Parliament Osteoporosis Interest Group's "call to action" is vital to encourage appropriate action at the national and European levels.

National osteoporosis policy issues are included in the audits, each of which has been completed by a national expert, many of whom were on the 1998 report expert working group. Facts and figures have been checked and the edited audits reviewed by both

the national experts and Dr Juliet Compston and Professor Socrates Papapoulos, co-editors of the 1998 report, for final comments and approval. Gaps and discrepancies in information reflect the low priority given to osteoporosis by governments and national health authorities. Most importantly, an update on the health related quality of life of the 15 osteoporosis patients and people at high risk of osteoporosis (one from each member state), who kindly appeared on the front cover of the 1998 report, is given.

The last three years have seen progress in some areas, most notably in the development of national guidelines in several of the member states, some improvement in the reimbursement of proven therapies and the number of DXA units in some of the countries and in the running of educational campaigns. However, as the tables of hip fracture numbers and direct hospital costs of hip fractures graphically illustrate, much remains to be done.

The number of osteoporotic hip fractures in the European Community has risen to over 480,000 annually, an increase of more than 25% over four years.



## Number of hip fractures (est.)

(\*latest available data – ranging from 1996 to 2000), (\*\*as reported in the 1998 *Report on Osteoporosis in the European Community*)

	<i>Annual Incidence*</i>	<i>1995 Annual Incidence**</i>
Austria	12,000	10,160
Belgium	13,120	11,930
Denmark	9,595	8,310
Finland	7,698	5,730
France	55,000	46,310
Germany	135,000	108,900
Greece	13,500	9,450
Ireland	2,777 (≥60)	2,678
Italy	78,478	38,130
Luxembourg	No info available	No info available
Netherlands	15,286 (≥55)	15,110
Portugal	8,500	6,040
Spain	30,460	30,460
Sweden	17,926	18,980
United Kingdom	86,408	69,600
<b>Total</b>	<b>485,748</b>	<b>381,788</b>

## Osteoporosis now costs more than Euro 4.8 billion annually in hospital healthcare alone – a staggering 33% increase over three years.

### Total annual direct hospital costs of hip fractures (est)

(\*latest available figures, based on data ranging from 1996 to 2000), (\*\*as reported in the 1998 *Report on Osteoporosis in the European Community*)

	<i>Latest available figure* (Euro)</i>	<i>1996** (Euro)</i>
Austria	156,000,000	146,324,320
Belgium	160,000,000	113,836,060
Denmark	47,975,000	47,975,000
Finland	150,000,000	22,685,070
France	600,000,000	560,860,410
Germany	1,462,240,000	1,401,978,600
Greece	44,550,000	47,817,000
Ireland	8,298,000	3,979,508
Italy	555,863,000	204,910,620
Luxembourg	No info available	No info available
Netherlands	180,375,000	180,375,000
Portugal	51,320,000	27,451,800
Spain	220,000,000	216,052,780
Sweden	300,000,000	101,030,540
United Kingdom	847,284,600	530,212,800
<b>Total</b>	<b>4.8 billion</b>	<b>3.6 billion</b>

Note: rehabilitation and nursing home costs are usually not included.

### Number of hip and spine DXA units per million population

	<i>2000</i>	<i>1997</i>
Austria	11.0	8.5
Belgium	20.0	18.5
Denmark	7.4	4.5
Finland	8.0	5.8
France	17.0	11.0
Germany	10.0	8.5
Greece	25.6	17.0
Ireland	5.3	3.0
Italy	10.5	5.8
Luxembourg	2.3 (1 for 0.44 million)	0.0
Netherlands	7.2	5.8
Portugal	25.0	13.0
Spain	8.0	7.0
Sweden	4.8	3.8
United Kingdom	4.2	3.5
<b>Average</b>	<b>11.1</b>	<b>7.7</b>

### What action needs to be taken?

There is great scope for the majority of European Union member states to significantly enhance the priority they afford osteoporosis:

- co-ordinated data collection and monitoring of osteoporotic fractures.
- educational campaigns and better training for healthcare professionals.
- availability of more DXA units, especially to deal with the problem of regional disparity.

In some countries more bone density (DXA) units are needed to ensure accessibility and lower waiting times.

But the most urgent challenge to ensure prevention of this painful, debilitating disease is to establish fuller reimbursement for bone density scans and for proven therapies prior to suffering the first fracture for the at risk population. In all of these areas the EU member states have plenty of scope for action in the coming years so that we can achieve our goal of reducing unnecessary fractures caused by osteoporosis and its subsequent economic burden

# Fuller reimbursement for bone density scans (DXA) is urgently needed.

## DXA scan of the hip and spine: reimbursement policy in the public health care system

	<i>Reimbursement</i>	<i>No reimbursement</i>
Austria	✓	
Belgium		✓
Denmark	✓ *	
Finland	✓ */**	
France		✓
Germany	partial reimbursement only after fracture	
Ireland		✓
Italy	✓ (over 65 yrs)	✓ under 65 yrs partial reimbursement (8%)
Luxembourg	✓ * 90% reimbursement	
Netherlands	✓ **	
Portugal	✓ (maximum cost of Euro 15 paid by patient)	
Spain	✓ (when referred by a specialist)	
Sweden	partial reimbursement	
United Kingdom	✓ **/*	

\* patients have to fulfill risk factor or other criteria, \*\* only budgeted number of scans are reimbursed, Greece: no official information available

## Evidence-based guidelines on diagnosis, treatment and care

	<i>no guidelines</i>	<i>produced by patient or scientific societies</i>
Austria		✓
Belgium		✓
Denmark		✓
Finland		✓
France		✓ in publication*
Germany		✓
Greece	✓	
Ireland		✓
Italy		✓
Luxembourg	✓	
Netherlands		✓ in production by non profit agency that produces health related guidelines
Portugal		✓ (for diagnosis)
Spain		✓ (but not followed by general practitioners)
Sweden		✓*
UK		✓*

\* endorsed by government agency

## Average waiting time for DXA scan

	<i>Public health care system</i>	<i>Private health care system</i>
Austria	4-12 weeks	4-12 weeks
Belgium	No waiting list	
Denmark	2-3 months	no info available
Finland	1 month	1 week
France	up to 4 months	minimal
Germany	ca. 1-3 weeks	
Greece	no official info available	
Ireland	up to 6 months	
Italy	3-5 months	ca. 10 days
Luxembourg	1-4 weeks	
Netherlands	3-4 weeks	
Portugal	1-2 months	1 week
Spain	6-12 months	no info available
Sweden	2 weeks-3 months	no info available
United Kingdom	2-3 months	2-3 weeks

## Reimbursement in the public health care system of proven therapies

	<i>Full reimbursement*</i>	<i>Partial or restricted reimbursement</i>	<i>No reimbursement</i>
Austria	✓		
Belgium		ERT (partial), Bisphosphonates and SERMS (min. 75% reimbursed) only after fracture or bone scan	calcium and vitamin D
Denmark		Only on an individual case basis which is bureaucratic and time consuming to administer	
Finland		50% reimbursed	
France		Bisphosphonates and SERMS only after fracture	
Germany		✓ <b>a</b>	
Ireland		Only after fracture	
Italy		Only after fracture	
Luxembourg		✓	
Netherlands	✓		
Portugal	✓		
Spain	✓ (over 65 yrs)	✓ 40% for those under 65 years	
Sweden	✓		
United Kingdom	✓ <b>b</b>		

\* generally based on reliable diagnostic procedures and only for approved/registered drugs, **a** limitation is imposed on the doctors who have an extremely low budget for prescription products and therefore are reluctant to prescribe drugs to prevent osteoporotic fractures. **b** with prescription charges for those under 65 years, Greece: no official information available

Proven therapies must be reimbursed before the first fracture.

## Key findings

- Little progress has been made on the majority of the eight recommendations published in the 1998 *Report on Osteoporosis in the European Community*
- Osteoporosis remains a neglected disease within Europe. No government has made osteoporosis a health priority.
- The number of osteoporotic hip fractures alone in the European Community has risen to over 480,000 annually, this is an increase of more than 25% over four years.
- Osteoporosis now costs more than Euro 4.8 billion annually in hospital healthcare alone (excluding rehabilitation and nursing home costs); a 33% increase over three years.
- A co-ordinated, dynamic, data collection system to monitor osteoporotic fractures across Europe is urgently needed to document the size of the problem and to monitor changes.
- The development of best practices to produce practical, cost effective strategies with measurable targets for reducing osteoporotic fractures must be implemented.
- Access and payment of bone density scans must be improved for people with osteoporosis risk factors especially before the first fracture.
- Payment of proven therapies for people with osteoporosis risk factors must be improved especially before the first fracture.
- Improved accessibility to diagnosis and proven therapies alone are not enough. Better education of policy makers, healthcare professionals and the general public is necessary to reduce osteoporotic fractures.

## Report Card – General analysis of progress made towards achieving the eight recommendations from the 1998 report.

Recommendations (see page 5 for full text)	Some Progress	No or little progress
1. Is osteoporosis a governmental health priority?	Germany, UK Spain, Sweden	Austria, Belgium, Denmark, Finland, France Greece, Ireland, Italy, Luxembourg Netherlands, Portugal
2. Fragility fracture statistics. Has a coordinated system for the monitoring of osteoporotic fracture rates been set up at a national level?	Austria, Denmark Finland, Netherlands	Belgium, France, Germany, Greece Ireland, Italy, Luxembourg, Portugal Spain, Sweden, UK
3. Cooperation and funding	Austria, Finland	Belgium, Denmark, France, Germany, Greece Ireland, Italy, Luxembourg, Netherlands Portugal, Spain, Sweden, UK
4. Calcium & vitamin D education	Austria, Finland, Greece Luxembourg, Spain, Sweden	Belgium, Denmark, France, Germany Ireland, Italy, Netherlands, Portugal, UK
5. Access to, and reimbursement of, bone densitometry systems	Austria, Denmark Finland, Luxembourg Netherlands, Portugal Spain, Sweden, UK	Belgium, France Germany, Ireland, Italy
6. Reimbursement of proven therapies for prevention/treatment	Austria, Finland, Luxembourg, Netherlands Portugal, Spain, Sweden, UK	Belgium, Denmark, France Germany, Ireland, Italy
7. Governmental financial support of osteoporosis patient and scientific societies/ training healthcare professionals	Austria, Belgium, Finland Germany, Luxembourg Netherlands	Denmark, France, Greece, Ireland Italy, Portugal, Spain, Sweden, UK
8. Research	Austria, Belgium, Denmark Finland, France, Germany Ireland, Italy, Netherlands Spain, Sweden, UK	Luxembourg, Portugal, Greece

# Multinational programmes and initiatives in Europe

To help address the limited progress, as set against the eight recommendations of the 1998 report, there are some European Commission work programmes which should include osteoporosis, some multinational initiatives involving osteoporosis supported by grants from the European Commission and some multinational initiatives supported by IOF and its partners. Summaries of some of these projects and developments are outlined here.

## European Commission work programmes which should include osteoporosis

### *Public Health Programme*

The Commission's new Public Health Programme, which is in the process of being adopted, provides the opportunity to include osteoporosis in several areas. The data collection and monitoring of osteoporotic fractures should be included in the proposed data collection and health information system. Prevention of osteoporotic fractures should also be included in the health promotion and disease prevention aspects of the programme.

### *Research Framework Programmes*

Osteoporosis has received some attention and financial support in previous Research Framework Programmes and should receive more attention in the future to address the rising number of osteoporotic fractures forecasted in the European Community as the population ages. A number of important projects have received funding from the European Commission over the last decade including:

- The European Vertebral Osteoporosis Study (EVOS) – a quantitative assessment of osteoporosis (Research Framework 2, early 1990s).
- Two grants on quantitative and qualitative assessment of osteoporosis (Research Framework 2, early 1990s).
- The European Prospective Osteoporosis Study (EPOS) – investigating bone quality (Research Framework 3, early 1990s).
- Project grants to allow the Czech Republic, Hungary, Poland, Russia and Slovakia to participate in EPOS; some funding for the Mediterranean Osteoporosis Study (MEDOS), Epidemiology of Osteoporosis (EPIDOS) and EVOS (Biomed 1, early 1990s).
- Hip fracture audit (Research Framework 4, mid-1990s).
- Genetics grant (research Framework 5, late 1990s).

### *'Direct to Consumer Information'*

Within the pharmaceutical review currently being debated, a section on 'Direct to Consumer Information' includes provision to relax restrictions on the availability of prescription product information for three specific therapeutic areas – AIDS, asthma and diabetes. Osteoporosis should also be included since it is a severe, chronic, progressive disease which can be prevented if actions are taken early. The greater availability of prescription product information on proven therapies for the prevention of osteoporotic fractures would make an important contribution to reducing the number of osteoporotic fractures in the future.

## Some current multinational initiatives supported by grants from the European Commission

### *European Bone and Joint Health Strategies Project*

On 5th February 2001 the European Commission signed a two-year project to develop a European wide strategy to reduce the burden of bone and joint disorders. To support this project the Commission made funding of €360,000 available. This project is being undertaken together with the Bone and Joint Decade (BJD), European League Against Rheumatism (EULAR), European Federation of National Associations of Orthopaedics and Traumatology (EFORT) and the International Osteoporosis Foundation (IOF). It will cover all aspects of musculoskeletal conditions, from prevention to rehabilitation, and will draw on expert knowledge and experience from all European Union member states. The project will be completed in May 2003 and will, it is hoped, lead to the implementation of health strategies, at national, regional, district and local levels that aim to reduce the impact of musculoskeletal conditions, including fractures caused by osteoporosis across the European Union.

Initially there are two key stages to the project. The first is to produce a background resource document. This will contain information on the incidence and prevalence of musculoskeletal conditions, identify priority areas, describe the range of intervention options at all stages that are currently available and give targets for prevention. Publication of this document is scheduled for the end of 2002.

The second strategic stage is to develop practical and appropriate policy recommendations from the information gained from the first stage. It is important that any strategies identified to tackle priority areas can be implemented at national, regional, district and local level across the European Union. Recommendations should allow for a variety of local interpretations and be appropriate to the needs of the local population. In developing the policy recommendations patients' views and resource implications will also be assessed.

### *European Union Health Indicator Project*

The aims of the Health Indicator Project are to provide high quality recommendations at national and European Community level for the monitoring of all musculoskeletal conditions. Osteoporosis will feature in the report as one of the important conditions. Risk factors to be monitored and the consequences of conditions will be discussed. The recommendations will outline a minimum and an optimal data set of recommended factors for monitoring musculoskeletal conditions.

The outcome will be an official report for the European Community Action Programme on Health Monitoring, published at the end of 2002. The report will be easily accessible for organisations and individuals working in the field. The countries taking part are: Austria, Belgium, Finland, France, Germany, Greece, Ireland, Italy, the Netherlands, Norway, Portugal, Sweden and the United Kingdom.

The European Commission grant for this project is €373,421, of which €102,000 is sub-contracted to the BJD.

### *Thematic Network on Male Osteoporosis*

Responding to the 8th recommendation in the 1998 Report on osteoporosis in the European Community, which highlighted the need for further research, including into male osteoporosis, a Thematic Network on Male Osteoporosis (NEMO) is being set up to research causes and treatment. This project is presently under consideration for funding by the European Commission, within the 5th Framework Research Programme.

The project aims to create a method for assessing the ten-year absolute fracture risk in men, based on a combination of risk factors. The method will form the basis of an outcome model for evaluating broad management strategies in male osteoporosis and be used, in a simplified form, in risk assessment in clinical practice. A collaborative multidisciplinary effort co-ordinating data from various existing research programmes will assess and establish the risk factors. Among the disciplines involved are: epidemiology, orthopedics, rheumatology, endocrinology, biology, geriatrics and radiology.

To establish the method and the outcome model, seven work areas are to be researched including:

- defining the extent and regional differentiation of male osteoporosis in Europe;
- physical measurement of bone mass and structure (using dual X-ray absorptiometry and quantitative ultrasound techniques);
- biochemical and hormonal markers of risk in male osteoporosis;
- heredity and its interaction with the environment (looking at family studies and larger scale population-based genetic epidemiology, using gene polymorphisms); and
- micro-architectural changes that underlie mechanical failure of bone in male osteoporosis.

There will be strong emphasis on integrating and disseminating information: in creating the risk assessment method and the outcome model; by producing an up-to-date, comprehensive scientific report on male osteoporosis and an interactive package for practitioners; and in disseminating information in collaboration with the International Osteoporosis Foundation. Participating countries currently include: Belgium, the Czech Republic, France, Germany, Italy, the Netherlands, Spain, Sweden, Switzerland and the United Kingdom.

### **Some multinational initiatives supported by IOF and its partners**

#### *Gender*

Osteoporosis is a gender bias disease, with one in three women, as compared with one in eight men, over the age of 50 suffering from the disease. Perceived by some as 'an old woman's disease', it has not always received the attention it deserves in the past. In 2000, the delegates of a European Institute of Women's Health (EIWH) conference unanimously agreed that gender should be mainstreamed in all health programmes and that it should be included in the new Public Health Programme and the 6th Research Framework Programme. In March 2001, EIWH tabled amendments on Gender in the European Parliament. These amendments stated that gender should be considered in data collection processes, that gender should be part of research criteria and that it should be considered as a determinant of health. The amendments were voted through in April 2001. A statement on gender has also been included in the 6th Research Framework Programme. The EIWH plans to apply for funding from the European Commission for a thematic network on gender.

#### *IOF Training Courses*

The International Osteoporosis Foundation conducts training programmes in partnership with national patient and scientific societies. Training programmes focusing on quality delivery of bone measurement services, osteoporosis treatment guidelines for orthopaedic surgeons to prevent new osteoporotic fractures and improved recognition and reporting of vertebral fractures by radiologists are being planned and starting to be implemented.

Despite these programmes at the European and multinational levels, the commitment of health authorities at the national level is essential to address the most urgent challenges which are to provide wider access/reimbursement to diagnosis and to proven therapies to people at risk of osteoporotic fractures prior to the first fracture.

**"... as population figures rise over the next years, so will the number of those affected. This forecast poses a daunting challenge to health policy, not only in Germany, but throughout Europe."**

# Conclusions and next steps



*Mel Read*

Mel Read MEP  
Founding Chair of the European  
Parliament Osteoporosis  
Interest Group

This audit has been conducted to analyse what actions have been taken by the fifteen European Union member states to move towards implementation of the eight recommendations published in the 1998 Report on Osteoporosis in the European Community. As the 1998 report clearly shows, osteoporosis is a severe, chronic, progressive disease which can be prevented if actions are taken early.

In 1998, at the request of the European Parliament, the Commission researched and published the Report on Osteoporosis in the European Community. All interested parties welcomed this initiative. However since then the suffering and cost of osteoporosis has increased at a staggering rate. For example, as reported in this audit, the number of osteoporotic hip fractures alone in the European Community has risen to over 480,000 annually, an increase of 25% over 4 years. Osteoporosis now costs more than Euro 4.8 billion annually in hospital healthcare alone, a 33% increase over 3 years. And of course with the ageing population this situation will get worse unless appropriate action is taken now.

This audit shows that national health authorities have made some progress in moving towards the implementation of the eight 1998 report recommendations. For example in some countries government and related agencies have developed guidelines for the prevention, diagnosis and treatment of osteoporosis. There have been one or two educational initiatives and more proven therapies have received marketing approval. However the actions taken are far from sufficient and much more needs to be done to prevent unnecessary suffering and to save national health authorities unnecessary expenses.

We must prioritise the cost-effective steps that are required in order to prevent unnecessary broken bones caused by osteoporosis. Fractures are the major clinical, painful, debilitating and costly outcome of this easily diagnosed and preventable disease. We need to make sure that the appropriate action is taken now.

Innocent people throughout Europe, represented by the case histories in the audit, suffer because they were not diagnosed or given proven therapies until after they had broken their bones, often several times. It is of the utmost importance to prevent the first osteoporotic fracture because recent studies show that once a woman suffers her first vertebral fracture there is a five-fold increase that she will suffer a second fracture within a year. Clearly our priority must be to prevent unnecessary suffering. European citizens must have the right to early diagnosis and proven therapies. This is why we call for national health authorities to set realistic time-based targets for reducing osteoporotic fractures.

One way to achieve this goal is through education. In order to prevent the projected two to five fold increase in osteoporotic fractures over the next five years, we need well-informed individuals, healthcare professionals and policy makers.

For these reasons I, along with the support of colleagues in the European Parliament, have decided to establish a European Parliament Osteoporosis Interest Group. This group, in partnership with the International Osteoporosis Foundation, Bone & Joint Decade, Business & Professional Women International, the European Institute of Women's Health, the World Health Organization and other concerned groups and professionals, will work hard to ensure that appropriate action is taken now, both at the national and European level.

## A call to action

**The European Parliament Osteoporosis Interest Group calls for the following specific actions to be taken:**

**In order to prevent the unnecessary suffering and costs caused by osteoporotic fractures national health authorities and health insurance agencies must:**

- **Improve the availability of bone densitometry resources and pay for bone density scans for people with osteoporosis risk factors prior to the first fracture.**
- **Pay for proven therapies for people with osteoporosis risk factors prior to the first fracture.**
- **Financially support and participate in educational awareness campaigns in partnership with the IOF-International Osteoporosis Foundation, IOF member societies and other concerned groups and professionals.**

**To help Member States to develop best practices and to evaluate the results of their actions the European Commission must work in partnership with the International Osteoporosis Foundation to:**

- **Bring national and European policy makers together with osteoporosis experts and concerned groups to produce practical, cost effective strategies to prevent osteoporotic fractures. These strategies must include measureable, realistic, time-based targets for reducing osteoporotic fractures.**
- **Create a co-ordinated data collection system to monitor osteoporotic fractures across Europe.**

The members of the European Parliament Osteoporosis Interest Group will act as osteoporosis ambassadors in their own countries and at a European level to assist health authorities, health insurance agencies and the European Commission in implementing this call to action over the next three years. After this period another audit will be conducted to monitor progress.

We sincerely hope that you will support us in this call to action and do what you personally can to implement the above actions.

## Acknowledgments and key references

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“IOF encourages health ministers to make osteoporosis a health priority in their countries. We have plenty of information about prevention, early detection and treatment. What we need now is more action from everyone. Together we can stop the pain, suffering and cost resulting from osteoporosis.”

#### The International Osteoporosis Foundation (IOF)

**IOF is a non-governmental umbrella organisation dedicated to the worldwide fight against osteoporosis. Working hand-in-hand with its scientific and corporate advisors, member societies, and other health-care related organisations around the world, IOF encourages awareness and prevention, early detection, and improved treatment of osteoporosis.**

**IOF motivates people to take charge of their own health and believes that this empowerment is the driving force behind the osteoporosis movement. IOF was launched in 1998 with the merger of the European Foundation for Osteoporosis (EFO, founded in 1987) and the International Federation of Societies on Skeletal Diseases. IOF's members currently number 124 national patient and medical societies from 66 countries.**

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