

OSTEOPOROSIS RESEARCH  
IN PARTNERSHIP WITH

**IOF**

International  
Osteoporosis  
Foundation



## HOW FRAGILE IS HER FUTURE?

A REPORT INVESTIGATING THE  
CURRENT UNDERSTANDING AND  
MANAGEMENT OF OSTEOPOROSIS  
AROUND THE WORLD TODAY

## CONTENTS

### 1 | BREAKING THE SILENCE

A foreword by Pierre D Delmas, M.D, PhD, President of the IOF

### 2 | INTRODUCTION

- What is Osteoporosis?
- Prevalence of Osteoporosis

### 3 | THE RESEARCH

### 4 | KEY FINDINGS

### 5 | WHAT DID THE POSTMENOPAUSAL WOMEN SAY?

- Awareness is high, but women's understanding of their personal risk is alarmingly low
- Physician communication fails to generate understanding or urgency about the long-term risks of the disease
- Women report the impact of osteoporosis is anything **but** silent
- Women have limited information about, and access to, screening and medication

### 6 | WHAT DID THE PHYSICIANS SAY?

- Physicians identify osteoporosis as a key health concern for postmenopausal women
- Physicians recognise the need for screening those at high risk and early intervention, but are constrained by limited resources
- Physicians consider the occurrence of fracture more important than the impact on a woman's quality of life
- Medication to prevent fractures is not being offered to women early enough
- Physicians cite patient concerns about side-effects and safety as obstacles to commencing therapy and compliance with long-term therapy

### 7 | RECOMMENDATIONS

### 8 | REFERENCES

The research in this report was undertaken by IPSOS-RSL, an independent market research company between March and May 2000.

The questionnaires were developed and approved in partnership with the International Osteoporosis Foundation and Lilly.

All findings presented in this report have been verified by IPSOS-RSL to ensure correct interpretation of the data.



## 1. BREAKING THE SILENCE

### A FOREWORD BY PIERRE D DELMAS, M.D., PhD, PRESIDENT, INTERNATIONAL OSTEOPOROSIS FOUNDATION

One in three women over the age of 50 will suffer an osteoporotic fracture<sup>1</sup>. As the population of the world ages, the absolute number of women suffering an osteoporotic fracture will increase dramatically.

The impact of just one fracture can be devastating on a woman's life, and may result in chronic pain and disability. In the past 10 years, substantial advances have been made in the identification of risk factors, in early diagnosis – before the first fracture, and in the development of new agents that are effective in both treatment and prevention of osteoporosis.

Despite these advances, many individuals with osteoporosis remain undiagnosed, and the disease is fast becoming a public health problem around the world. The International Osteoporosis Foundation (IOF) is delighted to be a partner in this international survey, which investigated women's attitudes, and physicians' current approach to the prevention and treatment of osteoporosis.

The research was conducted among both physicians and postmenopausal women in 11 countries across the world. The results, summarised in this report entitled, 'How Fragile is Her Future?' are disturbing, revealing that:

- Although one in three women will be affected by osteoporosis, eight out of 10 do not feel personally at risk for the disease.
- Many women currently at risk of osteoporosis are not being identified early enough to fully benefit from preventive or treatment measures.
- Despite an intention to prevent osteoporosis, doctors often do not prescribe a medication until a woman has already experienced a fracture.

By highlighting the gap between physicians' intentions and their actions, this report challenges us to review our current approach to both treatment and prevention of osteoporosis, and helps to identify the barriers to effective prevention and control of this disease.

The IOF will use this evidence in our continuing campaign to:

- Create a greater sense of urgency amongst women to seek education about their own risk of osteoporosis.
- Challenge current medical attitudes and prescribing habits in osteoporosis.
- Lobby governments for policy change on access to and reimbursement for appropriate early prevention strategies and medication.

It is only by ensuring that doctors, women, and public health policy makers alike give the highest priority to the prevention, detection and treatment of osteoporosis that we can hope to achieve our vision - a world without osteoporotic fractures.



Pierre D Delmas

## 2. INTRODUCTION

### WHAT IS OSTEOPOROSIS?

Osteoporosis is a systemic disease in which the density and quality of bone are reduced, leading to weakness of the skeleton and increased risk of fracture, most frequently in the spine (vertebrae), wrist, hip and pelvis<sup>2</sup>. The main cause of bone loss in women is the accelerated loss of estrogen during and after the menopause.

Osteoporosis is often called the 'silent epidemic'. For many of those affected, bone loss is gradual and may be without symptoms or warning signs. As the disease progresses, however, a woman's risk of fracturing a bone increases. One of the earliest and most common fractures is vertebral. Only one third of vertebral fractures come to clinical attention<sup>3</sup>, however, all vertebral fractures, even those that are not clinically apparent, are associated with substantial increases in back pain and disability<sup>4</sup>.

### PREVALENCE OF OSTEOPOROSIS

Statistics, from a sample population of both men and women, indicate that 46% of all diagnosed fractures are vertebral, 16% are hip fractures and 16% are wrist fractures<sup>5</sup>. Women who have already suffered a vertebral fracture are five times more likely to suffer a subsequent osteoporotic fracture, e.g. a hip fracture, than women who have not suffered a first vertebral fracture<sup>6</sup>.

Hip fractures generally occur around 15 years later than those in the vertebrae and wrist and almost always necessitate hospitalisation<sup>3</sup>. In many countries, fractures caused by osteoporosis are responsible for more days of hospitalisation among women over 45 years of age than any other disease. The annual combined medical costs of treating 2.3 million osteoporotic fractures in both Europe and the United States is currently \$27 billion<sup>7</sup>.



### 3. RESEARCH

The survey was conducted by the independent global market research company, IPSOS-RSL, between March and May 2000, and involved 1,071 physicians and 559 postmenopausal women in eleven countries around the world: Australia, Brazil, Canada, France, Germany, Italy,

Jordan, Lebanon, Mexico, Spain, and the UK. The average age of the women respondents was 60 years. Twenty five percent of the women interviewed were diagnosed with osteoporosis. For the purposes of this report, the women without osteoporosis are referred to as 'healthy' women.

#### 4. 'HOW FRAGILE IS HER FUTURE?': KEY FINDINGS

- Postmenopausal women acknowledge the serious nature of osteoporosis but do not recognise their own personal risk of the disease.
- The content and quality of doctor-patient conversation is not motivating women to identify their personal risks or take preventative/treatment action against osteoporosis.
- A gap exists between physicians' desire to prevent fractures caused by osteoporosis, and what is actually happening in practice. Physicians often do not prescribe preventative medication for osteoporosis until a woman has **already** experienced a fracture.
- Women with osteoporosis recognise the importance of early intervention and wish they had taken action earlier to protect themselves against the long-term health risks associated with the disease.
- There are a number of barriers which limit doctors' ability to detect bone loss early, and their decision to prescribe a medication to either prevent or treat osteoporosis. These include lack of time and limited access to and funding for bone mineral density screening and reimbursement for medication.
- While women express a willingness to take preventative measures, their concerns about the side-effects and long-term safety of medication may be barriers to commence therapy and compliance with long-term therapy.

**"The average age of women in this survey is 60 years. These women are most at risk of a vertebral fracture, with the subsequent negative impact on quality of life. It is critical that we detect bone loss early, and prescribe appropriate therapy to prevent the occurrence of a first vertebral fracture in order to protect their long-term health. The most appropriate therapy for these women will combine bone efficacy, along with long-term safety and convenience."**

Dr Ethel Siris, Professor of Clinical Medicine, College of Physicians and Surgeons of Columbia University

### 5. WHAT DID THE POSTMENOPAUSAL WOMEN SAY?

#### AWARENESS IS HIGH, BUT WOMEN'S UNDERSTANDING OF THEIR OWN RISK IS ALARMINGLY LOW

Postmenopausal women are almost unanimously aware of the serious nature of osteoporosis. However, while 93% of women agree that osteoporosis is a serious condition, 8 out of 10 do not believe that they are at personal risk from osteoporosis. In reality, one in two women over the age of 50 will suffer an osteoporotic fracture during her lifetime<sup>8</sup>.

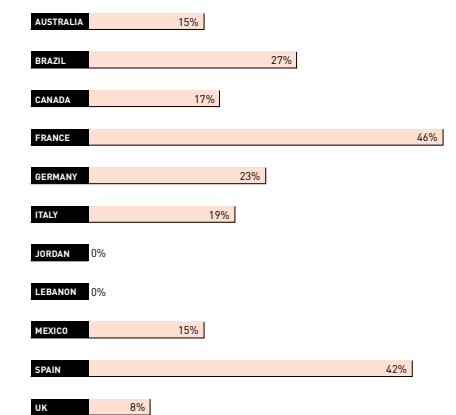
Among the women surveyed, 80% of those with osteoporosis had not been aware that they were at risk of the disease prior to diagnosis.

#### PHYSICIAN COMMUNICATION FAILS TO GENERATE UNDERSTANDING OR URGENCY ABOUT LONG-TERM RISKS OF DISEASE

The content or quality of communication between women and physicians is not sufficient in helping women consider their own risk of osteoporosis or the need to take preventative action. Less than a third of 'healthy' women had spoken to their physician about osteoporosis, and only 54% of women with the disease had discussed the long-term health risks of osteoporosis with their physician.

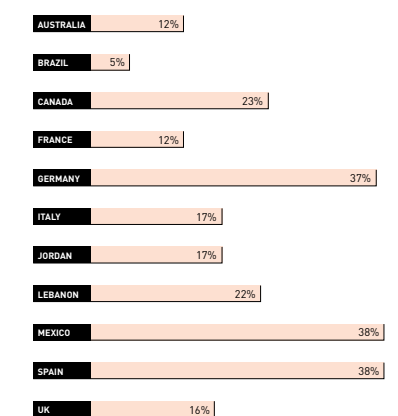
Percentage of women with osteoporosis who were aware they are at risk prior to diagnosis.

Base: Women with osteoporosis (n=139)



Percentage of women whose main health concern is osteoporosis

Base: All female respondents who currently have health concerns (n=417)



## WHAT DID THE POSTMENOPAUSAL WOMEN SAY?

### WOMEN REPORT THE IMPACT OF OSTEOPOROSIS IS ANYTHING BUT SILENT

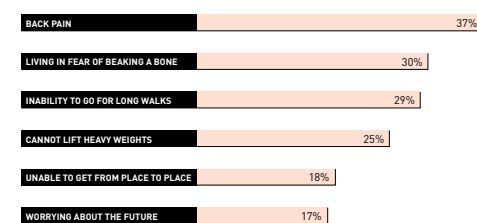
Osteoporosis affects a woman's ability to carry out even the simplest of tasks. Fractures are not always the result of a fall - picking up a bag of groceries or embracing a loved one can cause a woman with osteoporosis to break a bone. For Elge Pezzotti, a woman with osteoporosis from Italy, this is a high price to pay: "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'."

Women with osteoporosis recognise the need for early intervention - 81% acknowledge the significant negative impact the disease has had on their quality of life. Seventy-two percent would have taken a preventative therapy earlier if they had known that they were at risk.

Women report that the most negative aspects of living with osteoporosis include living in fear of breaking a bone, back pain, inability to perform everyday tasks, and the loss of mobility.

#### Impact osteoporosis has had on women's quality of life

Base: Women with osteoporosis (n=139)



### CASE STUDY: RANDA RABIE, JORDAN

Randa Rabie accepted her back pain as a result of a minor accident four years earlier. However, as Randa has a family history of osteoporosis, her doctor suspected that her pain may be due to a vertebral fracture caused by osteoporosis. An x-ray showed that Randa had suffered a previously undiagnosed vertebral fracture, and her bone mineral density test indicated osteoporosis. Randa encourages women to be aware of the long-term health risks for osteoporosis, and to talk to their doctors about the possibility of screening to detect whether they are at risk of fracture.

**"While we want to help women assess their own risk of osteoporosis and urge them to visit their doctor to discuss the disease in more detail, doctors also need to take sufficient time to explain to women the long-term impact of osteoporosis on quality of life, and to spend more time giving patients advice on the preventative measures they can take."**

Dr Ethel Siris

### WOMEN HAVE LIMITED INFORMATION ABOUT, AND ACCESS TO, SCREENING AND MEDICATION

Bone mineral density screening is used to assess fracture risk, confirm a diagnosis of osteoporosis and monitor the effects of treatment. Despite the large number of postmenopausal women at risk of osteoporosis, only seven percent of the 'healthy' women in the survey were spontaneously aware that they had been screened.

Clinical research has shown that current medications are effective in increasing bone mass and reducing the risk of fractures due to osteoporosis. Seventy-seven percent of women said that they would consider a preventative medication if their doctor recommended it, but only 2% of women who had discussed osteoporosis with their doctor

reported also discussing medication options. Even among women with osteoporosis, 33% are still not on any medication to treat the disease. The main concern about taking long-term preventative medication is the fear of side-effects, including concern about the perceived long-term risks of taking hormone replacement therapy (HRT).

**"The main goal of osteoporosis management is to prevent fracture. Lifestyle changes, such as maintenance of a balanced diet and weight-bearing exercise, may contribute to long-term bone health, but women at high risk of fracture, such as those with a family history of osteoporosis, may also require a pharmacological intervention."**

Professor Pierre D Delmas



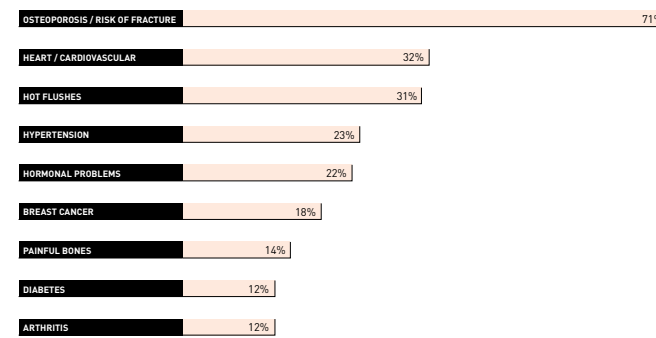
## 6. WHAT DID THE PHYSICIANS SAY?

### PHYSICIANS IDENTIFY OSTEOPOROSIS AS A KEY HEALTH CONCERN FOR POSTMENOPAUSAL PATIENTS

Nearly all physicians consider osteoporosis to be one of the key health concerns for their postmenopausal patients. Ninety-three percent of physicians said that fractures caused by osteoporosis represent a major clinical problem, and two thirds of physicians cited osteoporosis as a key health concern for postmenopausal women, more so than heart disease and cancer.

Health concerns for postmenopausal women considered most important by doctors

Base: All respondents (n=1,071)



### PHYSICIANS RECOGNISE THE NEED FOR SCREENING THOSE AT HIGH RISK AND EARLY INTERVENTION, BUT ARE CONSTRAINED BY LIMITED RESOURCES

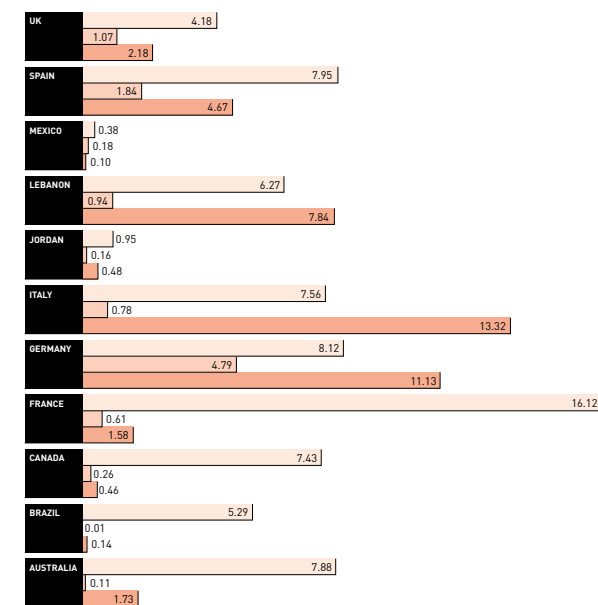
Physicians recognise the importance of early intervention to prevent osteoporosis, with 97% of physicians citing prevention of the first fracture as their goal. In an effort to achieve this, 65% report that they routinely or proactively carry out health risk screening among their postmenopausal women.

Nonetheless, three quarters of physicians stated that the level of and access to facilities for screening is considered to be inadequate. Eighty-three percent of physicians consider the level of funding for screening inadequate. A fifth of doctors said that lack of time limits the amount of health status reviews that they currently conduct among their postmenopausal patients.

Estimate of bone densitometry equipment (units/million population)

- Hip and spine units
- Forearm units
- Ultrasound units

Data consolidated by the International Osteoporosis Foundation



### PHYSICIANS CONSIDER THE OCCURRENCE OF FRACTURE MORE IMPORTANT THAN THE IMPACT ON A WOMAN'S QUALITY OF LIFE

When considering the impact of osteoporosis on women's lives, physicians focus on the clinical impact of fractures, and place less emphasis on the quality of life concerns than those expressed by women in the survey. Seventy-six percent of physicians view fractures as the most negative impact of osteoporosis; only 14% reported the limiting effect on lifestyle.

**“Osteoporosis affects all aspects of a woman’s life, and may result in chronic pain, fear, disability, and loss of independence. The impact is devastating, widespread, and increasingly costly to society. Why is this, when osteoporosis can be effectively treated and prevented? This report should challenge physicians to make greater appropriate use of risk assessment and screening tools to detect bone loss earlier, and to focus their discussions on the long-term consequences of osteoporosis. We must also urge women to take notice – and action.”**

Mary Anderson, Executive Director, IOF

### CASE STUDY: INGER LUNDEGAARDH, SWEDEN



1959  
20 years old

**“Osteoporosis first affected my life 11 years ago. After playing tennis my arm started to ache. I didn’t go to the doctor at first, but eventually I had an x-ray which showed that I had broken my arm.”**

Within six months, Inger had suffered three further fractures. Two of these fractures were not caused by falls, but occurred following light physical exercise – cycling and walking. A bone mineral density scan confirmed osteoporosis. To date, Inger has received one artificial hip, and she has lost 22cm in height.



1996  
57 years old

**“My daily life has changed completely. I now walk with two canes, I can’t bend down and I’m constantly in pain.”**

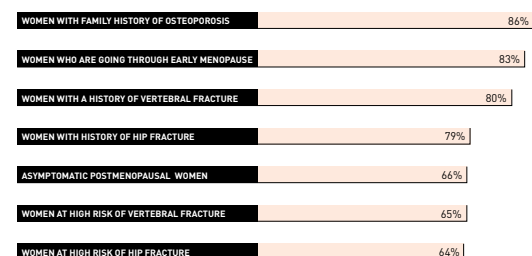
## WHAT DID THE PHYSICIANS SAY?

### MEDICATION TO PREVENT FRACTURES IS NOT BEING OFFERED TO WOMEN EARLY ENOUGH

Physicians estimate that 45% of the postmenopausal women in their practice are on preventative therapy and 42% are on a treatment for osteoporosis. While this confirms their intention to identify bone loss and prevent fractures, in many cases, it does not appear to be happening early enough. Eighty percent of doctors stated that one of the strongest indicators of an ideal candidate for a preventative medication is a woman who has **already** suffered a vertebral fracture.

#### Who is the ideal candidate for preventive medication?

Base: All respondents (n=1,071)



### CASE STUDY: ANNE O'DONOGHUE, IRELAND

60-year old Anne was diagnosed with osteoporosis five years ago following a medical examination at work. Anne's slight build and her maternal history of vertebral fractures concerned her doctor, and a bone scan confirmed that she was suffering from osteoporosis, and was at risk of suffering an osteoporotic fracture. Before her diagnosis, Anne had no reason to suspect that she was at risk of a fracture. Anne was recommended to take a medication to protect against fracture. Anne encourages other women to be aware that they can have osteoporosis without any symptoms.

**"My doctor recommended a bone scan early enough to identify that I was at risk of suffering a fracture, so I have been able to benefit from taking a preventative therapy."**

**"In the year prior to this survey, women with osteoporosis visited their physician almost twice as many times as women without osteoporosis. Taking the time to revisit the health status of a woman will lead to early identification of bone loss and the opportunity of intervention before a first fracture occurs. In the long term, this will result in fewer physician visits, and fewer hospitalisations among women, ensuring that they retain their independence throughout their postmenopausal years."**

Dr Ethel Siris

### PHYSICIANS CITE PATIENT CONCERNS ABOUT SIDE-EFFECTS AND SAFETY AS OBSTACLES TO COMMENCE THERAPY AND COMPLIANCE WITH LONG-TERM THERAPY

Osteoporosis is a lifelong disease, and women may need to take therapy over the long-term to achieve optimal protection against fractures. Aside from a product's ability to reduce the occurrence of fractures, physicians recognise the need for women to comply with medication to ensure long-term protection. Patients' unwillingness to take a long-term therapy was highlighted by 36% of physicians as one of the key challenges in prescribing preventative medication for postmenopausal women, and two-thirds of physicians highlighted tolerability, safety and convenience as factors which affect their decision to prescribe a particular therapy.

**"Fear of side-effects is very real for women when being prescribed long-term therapy, yet in order for them to realise the full benefit they must be prepared to take it consistently over time. Therefore, we must explain to women the long-term consequences of osteoporosis, and work with them to identify a therapy that both provides benefit and addresses their concerns."**

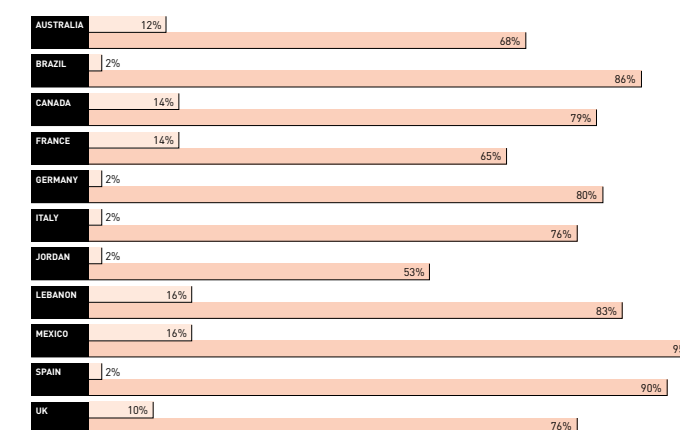
Professor Cyrus Cooper, University of Southampton, UK

#### Women who say they are on preventative therapy for osteoporosis

Base: All female respondents aged 41+ and been through menopause (n=559)

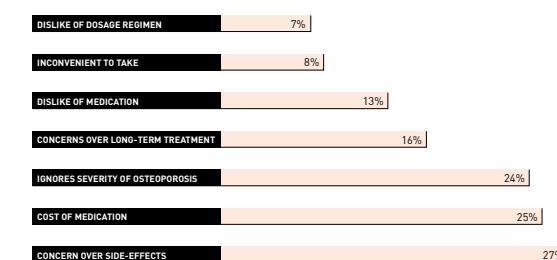
#### Women who say they would take it if their doctor recommended it

Base: Respondents not taking long term preventative therapy (n=512)



#### Reasons why women do not comply with long-term medication

Base: All respondents (n=1,071)



## 7. RECOMMENDATIONS

Osteoporosis is a widespread and costly public health problem. As the worldwide population grows and ages, the responsibility for managing the rising burden of osteoporosis will increasingly fall to the primary care physician. 'How Fragile Is Her Future?' highlights the barriers which must be overcome to ensure more widespread and effective prevention and treatment of this devastating disease, and suggests that the following course of action must be taken by physicians, governments and women alike.

1. Physicians should conduct a full health status review with every woman in their practice, as soon as she has gone through the menopause. In order to assess the woman's individual risk from osteoporosis, this review must include questions covering the following:
  - family history of osteoporosis and/or fracture
  - genetics e.g. body build
  - hormonal changes
  - medication
  - lifestyle, including diet and exercise regimens

All physicians should make use of a standardised risk assessment checklist, such as 'One Minute Osteoporosis Risk Assessment Test' produced by the IOF.
2. Physicians need to talk to women in a language they understand, taking time to explain the long-term impact which osteoporosis can have on a woman's ability to remain independent in later years. Doctors need to explain that bone loss may progress without symptoms, and use prevalence statistics to reinforce the widespread nature of osteoporosis to their patients.
 

When a physician identifies a woman who is at risk of a fracture, they must discuss with her the steps she can take to protect her long-term health such as lifestyle changes, the importance of having a bone scan, and the role of long-term therapy in reducing the risk of fractures. Patient organisations can play a pivotal role in this communication process.
3. Government and local health authorities need to provide increased support for national patient organisations and international patient networks. Additional funding should be used to support joint campaigns to increase awareness of the long-term health risks of osteoporosis among the target women, to help them understand their own risk from the disease, and to encourage them to visit their physician if they consider themselves at risk.
 

Governments should consider the use of local, regional or national spokeswomen to attract attention to such campaigns. In addition, information which encourages women to actively assess their own risk, such as the 'One Minute Osteoporosis Risk Assessment Test' should be distributed widely to postmenopausal women through target media and primary care waiting rooms as part of such campaigns.
4. Physicians should encourage women with osteoporosis, and women who have cared for someone with osteoporosis, to become involved in awareness campaigns, in order to highlight the impact osteoporosis can have on quality of life. These women can share their stories, to educate other women, to convey to physicians the importance of quality of life, and to raise funds for research and further public health campaigns.
5. Early detection of bone loss prior to a fracture will result in fewer hospitalisations among postmenopausal women, and reduced long-term costs associated with osteoporosis.
 

Governments must commit to making early detection of bone loss a top priority. This will include increasing the current provision of bone density scanning equipment, so that all women at risk of osteoporosis have access to these resources, as well as introducing local guidelines to ensure a consistent approach to the reimbursement of medications which are proven safe and effective for the prevention and treatment of osteoporosis.

## 8. REFERENCES:

1. Hall M. Target Osteoporosis. APBI, London, 1996.
2. International Osteoporosis Foundation. 1998 Annual Report.
3. Interim Report & Recommendations of the World Health Organisation Task Force for Osteoporosis. *Osteoporosis Int*, 1999; 10 (4): 259-264.
4. Nevitt et al. *Annals of Internal Medicine*, 1998; 128: 793-8003.
5. Riggs BL and Melton LJ. The worldwide problem of osteoporosis: Insights afforded by epidemiology. *Bone*, 1995; 17 (5): 5055-5115.
6. Black DM et al. Prevalent vertebral deformities predict hip fractures and new vertebral deformities but not wrist fractures. *Journal of Bone and Mineral Research*, Vol 14, 5; 821-828.
7. International Osteoporosis Foundation. World Osteoporosis Day Factsheet. 1998.
8. Chrischilles et al. *Arch Intern Med*. 1991;



