

WOMEN LEADERS ROUNDTABLE - 11.05.02

MEL READ

Colleagues, Good afternoon, I think we should make a start. My name Mel Read, I am a member of the European Parliament and I am Chair of the European Parliament's Osteoporosis Interest Group and I want to welcome you to this first International Osteoporosis Foundation Women Leaders Round Table.

Colleagues, I am honoured to be Chair of this distinguished group of ladies. Most of my colleagues here are going to be giving a speech so I will introduce each of them to you, just before they present, but because time is limited not everyone present this afternoon is able to present, so last night we heard from Maria-Elise Domingues who is a Member of the Parliament here in Portugal and we also heard from Anna Molinari, the Italian fashion designer. Both of these ladies have a personal link with osteoporosis as their mothers both suffered from the disease. Also Felicia Knaul from Mexico, who has a particular interest in health care policy, including osteoporosis couldn't be with us today but she sends her best wishes and apologies.

Colleagues we are now going to see a video from Regina Prado. She is the spokesperson of the Brazilian Osteoporosis Society. She couldn't be with us in person today because she is in a wheelchair after her sixth osteoporotic fracture. Now we are going to see the video.

REGINA PRADO

My name is Regina Prado, president of the Arthritis Support Groups for both the States of Rio de Janeiro and São Paulo, the two largest Brazilian states, and also spokesperson for the Brazilian Osteoporosis Society.

Unfortunately, the osteoporosis itself - given that I am an osteoporosis patient - prevented me from participating in this important event in person.

I have been a rheumatoid arthritis patient for the last 25 years. The continuous use of corticoids ended up by weakening my bones and caused severe osteoporosis.

I had my first fracture 12 years ago. In total, I had 6 fractures altogether since then. My most recent one - a fracture of my left leg shank bone - forced me to be on a wheelchair for six long months before the bone knitted. I can no longer climb stairs or walk long stretches or, either, for longer periods of time. My difficulty in moving around, as well as the long and painful recovery process I have been going through, did not make my trip to Lisbon possible.

You may gather from my words that osteoporosis is an issue that is very close to my heart and mind in my daily battle against the effects of this disease.

Countries such as Brazil are not prepared to properly prevent, diagnose and treat osteoporosis. We have no drug refund scheme and the government drug subsidy plan does not include any osteoporosis medication.

Well, ladies and gentleman, our major endeavor is to provide access to diagnostic tests and proven therapies against osteoporosis. We have all tried very hard to change the current situation and I hope you will join us to develop similar campaigns in your countries.

I thank you for the opportunity I was offered and I hope each one of you will help in developing this important campaign.

MEL READ

Thank you Mrs Prado. Thank you very much indeed for that and we all wish you well.

Colleagues the challenge we face today is that in numerous countries around the world women do not have access to diagnosis or access to proven therapies for osteoporosis until after the first fracture. Unbelievably many women experience unnecessary suffering caused by broken bones as we have just seen because they did not know they had osteoporosis until after a fracture. This also results in unnecessary expense to Governments and health insurance agencies because broken bones are expensive to mend and the problem will only get worse as populations around the world age.

The purpose of this meeting, colleagues is to announce a Call to Action, to urge policy makers around the world to make the diagnosis and treatment of osteoporosis a priority on public health agendas, so that the first fracture is prevented. Today's call to action geographically expands the European Parliament Osteoporosis Interest Group's call to action which was announced at the end of the last year and I was proud to be associated with that.

Now our guest speaker, Pierre Delmas is Professor of Medicine and Rheumatology at the Claude Bernard University in Lyon in France and he is President of the International Osteoporosis Foundation.

Professor Delmas is a world, perhaps the world expert on osteoporosis and he will now explain to us just why it is so important to prevent the first fracture.

Professor Delmas.

PROFESSOR DELMAS

Thank you for this kind introduction and first of all let me thank you, all of you for being here. It's really a great privilege for the scientific community to have your support and on behalf of the 5000 scientists that are attending this meeting, thank you very much.

Why are we here? Because osteoporosis is a major public health problem and in the next few slides I will try to show you the facts.

First of all, osteoporosis is a growing problem and it's a growing problem worldwide. What you can see on this slide is that the number of hip fractures will increase tremendously in the next few years if we are not effective in diagnosing and treating the disease and you can see that the growth will happen, not in Europe, not in North America but also and mainly in Latin America and Asia, so it's really a global problem. Now the, if we try to compare osteoporosis to other chronic diseases associated with ageing that are much more well known, you can see on this slide, that actually, and these are data from the US, that each year there are more osteoporotic fractures, much more, than heart attacks or stroke or breast cancer. This is an extremely frequent disease. Now it is also a killer and what you see here is that actually the risk of a 50 year old woman to die from a hip fracture is as great of her risk of dying from breast cancer and much higher than her risk to die from uterus cancer.

Now it's not only a question of death, it's a question of mobility. Osteoporosis is a crippling disease and what is captured on this slide is that with the osteoporotic fracture actually relating throughout life the disease becomes really crippling and many of these women will end up being bed ridden. Now, for example, those women that survive from a hip fracture, you can see here that a majority of them will lose their autonomy, they will not be able to walk, to climb stairs by themselves which of course will lead to a major impairment. What has been ignored in the past few years is the disability associated with vertebral fractures. Vertebral fractures are actually the most common osteoporotic fractures, they are more common than hip fractures. They will lead to *kyphosis* as you can see from back of this woman, loss of height, a lot of deformity, leading to not only acute bone pain during the fracture but chronic bone pain in between and leading to breathing difficulties, leading to actually an increased risk of death and overall a major impairment of their quality of life.

Now the occurrence of a vertebral fracture should be a red signal because it will increase tremendously the risk of subsequent fractures. It

will multiply the risk of a vertebral fracture by five and we know that one woman in five will suffer from another vertebral fracture within one year. Unfortunately we also know that 30% of these vertebral fractures are not diagnosed, and we need to do better.

Now just to show you, I have picked up one survey that was performed in the US in 1000 osteoporotic patients and amongst these patients that already suffered from a fracture, more than 80% feared another fracture. They feared that they could lose their independence or their ability to perform daily activities and you can see that 91% of them wished they had known about the disease before it happened.

Its also a very costly disease with a very huge burden on our resources, again just one example from a study done in Switzerland, if you look at the number of bed days in hospital you can see that osteoporosis is a major disease. If you look at men and women together, only chronic obstructive pulmonary disease results in more bed days, but if you look at women, unfortunately osteoporosis is the number one. Again this is extremely costly for our communities.

Now this is the bad news, hopefully we have some good news. And the first good news is that we can detect osteoporosis before the first fracture by measuring the bone mineral density by this technique which is called DEXA. This is a simple and very effective test. Now the other good news is that now we have treatments, both bisphosphonates and serms have shown that they can reduce the risk of subsequent fractures by up to 50% which is a major effect.

Now so we have some bad news, we have some good news, but the problem is the perception of the disease and I guess that's why we are here today.

As you can see from this survey conducted by IOF, 92% of women said yes they acknowledge that it's a serious disease, but 8 out of 10 do not believe they are personally at risk, while we know that 40% of them will have a fracture. So there is a discrepancy, we have also a major problem, which is illustrated here, in that we don't have enough access to the diagnostic tools and to the treatment.

This is shown in the survey that we performed in many countries around the world, showing that 75% of the physicians thought that their screening tools were not enough available. 83% of them said that the level of health care coverage was inadequate and we know that in many countries the measurement of bone mass is not reimbursed, we know that in many countries, the effective treatments for osteoporosis are not

reimbursed before the first fracture. So clearly we have a challenge because if these patients are not diagnosed then they will not be treated and we have actually data showing that this is the case. Look at this survey performed in sixteen so called wealthy European countries. Look at the proportion of osteoporotic patients that are treated on a regular basis. In 13 out of these 16 countries, less than 20% of the osteoporotic patients are treated adequately. In two countries between 20-25% of the patients are treated and in no single European country more than 50% of the patients are treated. So what we can say is that the awareness and the treatment of osteoporosis is inadequate despite a known disability, excess mortality attached to both hip and vertebral fractures, the high cost, effective diagnostic tests and ability of effective treatment.

Now amongst the IOF missions there is of course the need to support our national societies to fight osteoporosis. We need to increase the awareness and the understanding of osteoporosis and we need to motivate people to take action. And I must say that among these various activities one of them that has been very successful is the 206 bone fund where we have wealthy donators that contribute to this fund and with that fund we can expand on the research projects that are implemented throughout the world. Now, this 206 bone fund could be launched only because of the dedication of the President of this 206 bone fund who is Mrs. Hariri, sitting on my left. Now 206, why 206? Because we have 206 bones in our skeleton. Now up to now thanks to her skills and dedication we have 25 members and on behalf of the board of the International Osteoporosis Foundation I would like to declare that Mrs Hariri is the first IOF Ambassador.

Applause.

Thank you very much.

MEL READ

Professor Delmas thank you very much and all our congratulations go to you Mrs Hariri. We are going to hear from you in a moment or two, but I want now to ask Her Majesty Queen Rania of Jordan if she will make a few remarks. She is the host of today's event and Patron of the International Osteoporosis Foundation and it's a special honour for me to invite you to speak, and you know, I am sure from all of us how much your patronage and work is much appreciated. Your Majesty.

QUEEN RANIA

Thank you. Let me first say hello and welcome to all of you and thank you for taking the time to join us here today. I'd like to extend a special thank you to the members of the media who have joined us and whose support we are relying on to spread the message on this terrible disease. I'd like to thank the IOF sponsors who have made this meeting possible and my distinguished colleagues on this round table. I am glad to see so many old friends, women who have worked relentlessly on this issue for many years now. I am also delighted to see new faces. You are a sign of how much our global alliance has grown and the leadership that is contributing to success.

Gathered in this room is immense energy and intellect and capability. You are the backbone of this movement and I believe that with your help our movement will only become stronger and stronger.

Our meeting today draws on women's experiences and insight about the challenges of osteoporosis and the directions we should take. And this is tremendously important because history shows that only when women are active advocates for health care do our concerns get the attention and priority they need in research in developing diagnostic and treatment options and in providing services and covering the costs. Women's leadership is especially important when it comes to osteoporosis because this is a disease where prevention is key and prevention only succeeds when women are directly involved, informed and respected. For millions of families around the world it is the women who have the main role in household diet and other activities like exercise that build healthy bones. It is women who educate daughters. It is women who manage health care for older parents, but women have another important role and that is to spearhead change. We are the ones who can keep the focus of the research world, the medical community, Government and the private sector on this terrible disease.

We just saw the video about all that Regina Prado had experienced due to osteoporosis. Her story is tragic but more than that it is an outrage. This Congress and all its participants are providing abundant evidence of a scientific, diagnostic and treatment advances that are making this kind of suffering unnecessary. Yet everyday millions of people like Regina, men and women in every one of our countries are losing their mobility, their independence, their hope and in many cases their lives. The key to ending this tragedy, as all of us involved with IOF know so well, is to take action before the first fracture. First to prevent, to diagnose early, to make effective treatment available. Second, we must continue doing all we can to promote research and development into

new diagnosis and treatment options. Our aim should be to reach even more people even more effectively, again before the first fracture.

If you look around this room and this round table, you will see many of the people who will be important in this field, through their leadership, commitment and professional work. Again I would like to thank you very much and I look forward to all you have to contribute today and in the days ahead.

Thank you.

Applause.

MEL READ

Your majesty Queen Rania thank you, thank you very much for that, you are right to describe this round table as the backbone of the osteoporosis movement - an appropriate analogy.

Now we're going to hear from Mrs. Hariri who like so many others has been an inspiration and the honour, which has just been bestowed on you, is richly deserved. Mrs Hariri, would you like to address us.

MRS HARIRI

Your Highness, ladies and gentlemen. I am pleased and honoured to be with you today in this gathering of distinguished personalities in the field of medicine, press and social activities.

When I accepted to launch the campaign against osteoporosis I was driven by the objective of preventing large segments of population, especially the most needy, from being affected by consequences of this dreadful disease and sparing them unnecessary suffering. I deeply believe that what anyone could offer in the particular case of fighting osteoporosis, or in any cause which serves human beings in general is indeed a duty. A duty performed in gratitude to God, the ultimate source of help and well being and consequently no thanks or appreciation should be expected. I am pleased to point out that the 206 bone fund programme has received a very positive reaction from distinguished persons who rose to the call and who showed utmost understanding and generosity to make our initiative a big success. These contributions supported the awareness campaign, reinforced the capacity for research into the disease and allow the national osteoporosis societies to treat afflicted people without differentiation among people and religions.

Finally I should like to give my sincere thanks to Professor Pierre Delmas and to the International Osteoporosis Foundation for choosing me as first Ambassador of the IOF and please allow me to pay tribute also to the 30 personalities who joined me in realising this great achievement.

God bless you.

Applause.

MEL READ

Thank you very much indeed Mrs Hariri and congratulations again on your appointment. Colleague another person here today who has also worked tirelessly over the years to improve the recognition of osteoporosis is our next speaker, Mrs Camilla Parker-Bowles who is President of the National Osteoporosis Society in the United Kingdom. Mrs Parker-Bowles will speak to us about her family experience of how osteoporosis ruins lives.

Mrs Parker-Bowles.

MRS PARKER-BOWLES

Thank you.

Your Majesty. Ladies and gentlemen. I became involved with osteoporosis after my grandmother and my mother both tragically died as a result of this crippling disease. My Mother was only 72. Then, only 8 years ago, osteoporosis was seldom discussed, rarely diagnosed and usually attributed to old women with so called "dowagers humps". My family knew nothing about osteoporosis. The local GP was kind and sympathetic but he, like us, was able to do little to alleviate the terrible pain my mother suffered so stoically. We watched in horror as she quite literally shrunk in front of our eyes. She lost about 8 inches in height and became so bent that she was unable to digest her food properly, leaving her with no appetite at all.

In her latter years she could not breathe without oxygen or even totter round her beloved garden on her zimmer frame. I believe, ladies and gentlemen, that the quality of her life became so dismal and her suffering so unbearable that she just gave up the fight and lost the will to live.

As a result of my Mother's death, I became determined to find some way of helping people with osteoporosis from experiencing the same fate and general disregard that she encountered. I was lucky enough to discover on my doorstep the National Osteoporosis Society, a relatively new and small charity, piloted by the indomitable Linda Edwards. I went to visit them at their headquarters near Bath. I was so impressed by the dedication of their staff in helping both sufferers and their families and the research they were doing in the field of osteoporosis that I offered to help them in any way I could. Bravely they took up my offer.

As a Patron and now as President of the Osteoporosis Society I have had the chance to see for myself the wonderful care given to patients and I believe, exceptional ground-breaking research being carried out in hospitals all over Britain. On these visits we try and target local health authorities to encourage them to give more funding to osteoporosis. I am happy to report that with a bit of gentle nudging we have had a certain amount of success. But, as all of you here today know, we have a long, long way to go. There are not enough DEXA scanners, not enough staff to monitor, not enough physiotherapists, or special nurses, or money to help fund the vital research into osteoporosis itself.

So it is imperative that all of us at this IOF conference today, get this message across to our Governments and health authorities, by whatever

means we can. We must emphasise the importance for spending more money on early diagnosis, which is not just a huge saving in bone fractures alone, but could prevent the suffering my mother, grand-mother and thousands of people world-wide have, and had to endure.

Thank you.

Applause.

MEL READ

Mrs Parker-Bowles, thank you, thank you for that moving account, which of course is replicated in so many families around the world. Thank you.

Now it gives me great pleasure to introduce Maxine Mckew who is the award winning journalist and Patron of Osteoporosis Australia. Maxine is going to talk to us about the economic cost of broken bones in Australia. We are delighted to welcome you.

MAXINE MCKEW

Thank you Madam Chair and good afternoon everyone, your Majesty.

The story I have to tell this afternoon as Mel has said is about the economics of this disease and in fact this is something that I can say we have a handle on in Australia.

What we have done in Australia in the last year is to commission a report by one of our independent think tanks, Access Economics, and it really has given us quite an accurate, and I might say a startling picture of where we're at, and of course some of the figures I am going to put up here will follow in a rather interesting way from what we heard from Pierre before.

The report was called "The Burden of Brittle Bones". This was the first time that Australian data was compiled on both the economic and the social impact of osteoporosis and it was compiled from a number of sources, from epidemiological research, from data obtained from the Australian Bureau of Statistics, from material from hospitals and Government sources and from various research based papers compiled in Australia and internationally.

The picture we have is that as of last year, two million Australians have osteoporosis. Now we have a large country but a small population, 20 million. So we're talking about 10% of the population. The projection is that will go to 13% of the population by 2021 if nothing is done. I'll just give you a working definition, when I say people are suffering from osteoporosis, two million, what I'm saying is that in fact we're talking about those who have a bone density limit below that of an average healthy 40 year old individual.

Now what are the costs of this? Well the direct costs are totalling 1.9 billion dollars per annum. Of course the heaviest burden falling on hospitals and nursing homes. That translates in indirect costs to 5.6 billion, I'm quoting Australian dollars there, its about 2.8 billion US. Slightly more of course in Euros. Now I'll tell you why this has given us a wake up call, because up to say two years ago we were quoting costs of about a billion dollars. So you can see that these new figures have had quite an effect on all of us.

The indirect costs represent 1.2% of gross domestic product as of last year. Over a billion dollars in lost potential tax revenue. That's of course from lost earnings due to early retirement, income tax foregone, things such as that. We also know that osteoporosis is more expensive

than either diabetes or asthma, and of course both those diseases in Australia are national health priorities, but as at the moment osteoporosis is not.

Now that of course, what I've outlined is the cost to the public purse. If we look at the cost to individuals, osteoporosis is costing Australians 25,000 years of healthy life. That's in the past year. By that I mean disability adjusted life years, with over half of these due to premature death, disability and disease. We know that more years of healthy life are lost in Australia from osteoporosis than to parkinsons, HIV Aids, rheumatoid arthritis and cervical cancer.

Osteoporosis is more prevalent than high cholesterol, allergies or the common cold, and there are similar figures, I gather in both the US and in Europe. We know that muscular skeletal disorders, including osteoporosis, are the third leading cause of health system expenditure in Australia just behind circulatory and digestive diseases.

Here is snapshot of what all of this means. In 2002 someone is admitted to hospital with an osteoporotic fracture every 8 minutes. That is likely to rise to 1 in every 3.7 minutes by 2021 again if nothing is done. That's one in three hospital beds occupied by someone with an osteoporotic fracture. The numbers of fractures increasing at a rate, we estimate of 4% per annum and 83% increase in hip fractures by 2011.

And of course just to emphasise again the cost to the public health dollar of all of this indirect costs are conservatively estimated at nearly 6 billion dollars including things such as early retirement the cost of carers etc. Nearly 26,000 disability adjusted life years. This represents 1% of the total burden of disease and injury in Australia. In 1998 those figures there, 85,000 Australians were classified as disabled due to osteoporosis.

Now who are these people? Who are the people who are suffering? Well of those 85,000 Australians in fact we know that 80% of these people are on low incomes and in fact incomes of less than \$15,000, so you can imagine what it means to them to pay full costs for things like bone density scans. The high figure of this low income accounts for the fact that most are older sufferers, people living on small pensions and small retirement benefits. We also happen to know that there's 50% greater prevalence in urban areas than in rural areas and we're still speculating as to what the reason for that in fact might be.

What then is are the biggest problems that we've identified in Australia? Very similar to what Pierre has already outlined. The first problem of course is that the DEXA bone density test is only paid for in Australia under very narrow criteria, in fact the 4 categories you certainly have to

have had a fracture or a previous diagnosis of osteoporosis, have been on corticosteroids for over three months or some other medical condition.

The second major problem of course is that a majority of osteoporosis drugs are only paid for on our subsidised pharmaceutical benefit scheme after the first fracture. So what's to be done?

As of November last year, Osteoporosis Australia formed the bone mineral density industry key bodies round table and that is designed to work with all parties and with Government officials to widen the criteria for medicare rebates for BMD testing and that submission is presently before Government. Now this coincides with a very strong lobbying campaign with industry groups to have subsidised drugs on as I say on our PBS scheme, which is our pharmaceutical benefit scheme. To have this of course for prevention as well as for treatment of osteoporotic fractures. Now both these initiatives have been received favourably, as well they might because you can see from the figures that I'm talking about, that there is certain urgency to all of this. You can see that in fact we are well and truly behind the Ape wall in terms of asking individuals to wait for the first fracture to occur before granting rebates, or before access to subsidised drugs.

I'll just end on this final note, again very similar to what Pierre said before. The news poll studies in Australia. Awareness of osteoporosis as a disease among women and this is interesting, among women in the age group 30-55 where there is a high awareness of other significant health issues, over 90%. However, the news poll survey shows half of these women say its not a problem for me. So awareness is not being translated into action. I have had some background with breast cancer action groups and osteoporosis in Australia, quite frankly, is where breast cancer was 10 years ago. Which is why I will unhesitatingly be signing the call to action this afternoon, asking our policy makers to get their act together.

Thank you very much.

Applause.

MEL READ

Thank you Maxine those figures were really sobering and echoing so much of what Professor Delmas presented to us and you're right that we are where the breast cancer movement was 10 years ago. We need to catch up is the message. Thank you for that.

Now colleagues, we're going to hear from Maureen McTeer. She is a medical law specialist and an author and also spokesperson for the Osteoporosis Society of Canada and Maureen will enlighten us about the 'No Fracture is Acceptable Campaign, which has been running in Canada for two years and how today's Call to Action provides further impetus to stimulate improved access to diagnosis and to proven therapies to prevent that first fracture.

Maureen we look forward to hearing from you.

MAUREEN McTEER

Thank you very much Mel and thank you colleagues for your presence here and thank you in particular to you Queen Rania for your invitation to Canada to participate in this international roundtable session and for your own work as Patron of the International Osteoporosis Foundation. Your efforts are known to all of us and appreciated by all of us and we thank you.

This of course is an important and symbolic gathering of women from several countries. It provides us with an opportunity to raise in a very public way the nature of osteoporosis and its scope and impact, especially on women in our societies. But this meeting has a larger purpose than simply raising awareness of osteoporosis and its crippling and often fatal results for the one in three women and one in eight men internationally, who suffer from it. We are here to take concrete steps towards all of our governments and the international agencies who particularly deal with women's health to act now, to ensure early and accurate diagnosis, effective prevention and treatment and funding for research into osteoporosis.

Twenty years ago this June when the Osteoporosis Society of Canada began its pioneer work as the first national osteoporosis organisation in the world, Canada had just passed its charter of rights and freedoms that guarantees both procedural and substantive equality to all Canadians. Access to health care was not then seen as a rights issue. Now we know that discrimination can take many forms and affects different individuals and different groups differently. Because osteoporosis has traditionally been labelled as a disease mainly affecting elderly women its diagnosis and treatment has not been a national or an international priority. Thanks to the work of groups like those we are representing here today that situation is changing.

In Canada for instance the "No Fracture is Acceptable" campaign that is led by the Osteoporosis Society of Canada, whose executive director Joyce Gordon is here with us today, created an awareness of the critical issues of access to diagnosis and access to treatment. The campaign successfully moved several provincial and territorial governments in Canada to provide improved access both to diagnosis and to the medication that is required by those suffering from this disease.

But as my colleague, Camilla Parker-Bowles has mentioned, much work remains. Our collective call to action today, provides further encouragement to all of us working in the field, to address these critical

issues with policy makers in our country and beyond. This meeting and the Call to Action that we are signing today reminds all governments that diagnosis and treatment of osteoporosis is a critical health care priority. Each of us of course, must continue to work hard in our own countries and in our own media to make sure that the call to action that we are signing today becomes reality.

That is why I'm pleased to be able to join you here today to share with you what the Osteoporosis Society of Canada and its supporters across our vast land plan to continue to do in the months and years ahead, to move this agenda forward.

Upon our return to Canada we will meet with the Federal Health Minister, the Honourable Ann McClellan in our capital to brief her and to seek her support and that of our Government for the substance of the call to action that we are signing here today.

Second because in Canada, as in some other countries, health care is in fact a provincial responsibility. We will seek meetings with all of our provincial health ministers in the coming year to ensure that they understand the key messages of the "No Fracture is Acceptable" campaign and to demonstrate to them in a real way the Call to Action we are signing today has in fact not just a global scope but a local importance.

Third as part of that dialogue we will work with selected departments of health to ensure that the drug therapies that have been proven to reduce the risks and to improve the outcomes associated with osteoporosis can be covered under our publicly financed health care insurance schemes.

There's no use improving the diagnosis of osteoporosis if we in fact refuse to pay for the treatment. Our goal remains to prevent a first fracture and of course we will continue to urge governments everywhere to do this. The poorest Canadians are women who are single, widowed or divorced over the age of 65. This is one of the groups who is also at greatest risk for osteoporosis. I believe we have an obligation to ensure that they receive the best diagnosis and the best treatment. That will cost money because we want the most effective drugs covered, not just the least expensive. Women should not have to choose between food and the drugs that they need to treat the diseases that ravage their bones.

Fourth, we will meet with the President of the Canadian Institutes of Health Research, Dr Alan Burnstein to discuss how we can work together through research to improve women's health and to combat

osteoporosis and finally the Osteoporosis Society of Canada will continue its ongoing efforts to increase awareness as to the causes of osteoporosis, to improve current technologies and of course to ensure that there are options for both prevention and treatment.

We around this table are very lucky women. We have both the affluence and the influence to be here today to join our voices together to call on our governments and on the worlds international institutions to address osteoporosis as a major public health and social priority. The statistics speak to its prevalence and its impact on the lives of millions of women and increasingly we know, on the lives of millions on men in our countries.

Some around this table, as we have heard so eloquently, live with this disease and have seen their mothers and grandmothers bend and break under the pressure of disintegrating bones. Osteoporosis is about women's health but its also about women's equality. I am personally honoured to be able to join my colleagues here today and I'm equally honoured to be here on behalf of the Osteoporosis Society of Canada. We stand united with you in our pledge to continue to go beyond the awareness stage and to press for action by governments, nationally and internationally. In the coming two years before we meet again we will work to enshrine this Call to Action that we sign today, into our countries health care agenda and will provide all our governments with the information they need to help us attack and to eliminate osteoporosis.

Thank you.

Applause.

MEL READ

Thank you Maureen its very encouraging to hear how our Canadian colleagues will use today's Call to Action to stimulate health care policy change and I think you have provided us with ideas we can all think about adapting and using in our own countries, that was so positive. Thank you for that.

And now it gives me great pleasure to introduce Professor Rita Sußsmuth who is former president of the Bundestag in Germany.

Professor Sußsmuth

End of tape side one.

Tape side 2.

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PROFESSOR RITA SUSSMUTH

Your Highness, Ladies and gentlemen, its right it's the first time I joined this group and I'm committed to this work. Let me say briefly its correct in the time I was Minister for Health it was impossible to bring it really on the agenda. It was in the 80's and you all know if something is women's issue and that's true for health research and health policy, its at the end of the agenda never as priority.

So its still the case in my country and I think it's the right moment to show commitment and to change and I'm very pleased and honoured to join you and let me express first to Your Highness, but also especially to Mrs Hariri, it showed me once more we are a world family, a global family and its not Europe or United States of Canada; we belong all together and sometimes small countries having so much other diseases are much powerful and going forward than we are doing in our world prospect countries. Thank you very very much for this commitment and we can learn from one another. That's the best we can do in an international community.

Let me say the data already shown is the same in Germany and I am very grateful to Professor Pierre Delmas in which way he showed us the precise data we all have. We don't have a lack of knowledge but of implementation and therefore I think I listen to you being aware it concerns a lot of other women and men.

But let us start earlier, because we have already children and younger people afflicted from this disease and therefore as we have tests, as we have tools to find it out, persons at risk, why don't we apply them? And of course it is always said, it's a question of cost. You have to prove that the treatment is effective, but let me say it is proved.

We now need political commitment and political awareness and as in Germany 4-6 million people suffer from osteoporosis. 2 million women and 1 million men have to cope with vertebral fractures, it's the time to act and we don't need further discussions but we need national campaigns. I think in Germany, a really a small group of experts, researchers as you know, they are here they participating in the conference and really committed non-experts, bringing forward osteoporosis on the agenda, and of course Mrs Parker-Bowles, the most committed people are those who have experienced how people suffered in the families, among friends, in the neighbourhood and I think it is not necessary.

We can prevent, we can treat at the different levels and so why don't we do it? So it's really high time to react and you showed the cost. We could show you the cost in a large measure, but we also in my country, we only pay after the first fracture, instead of doing the opposite. So I think, and I come back to this joint action, the Bone and Joint Decade, also in Germany the network, the Bone and Joint Decay, has selected osteoporosis as the first bone disease to be addressed in my country due to the dramatic data that exists.

And so the International Osteoporosis Foundation provides a broad platform, not only international first class scientists for all related disciplines to meet voluntarily in order to change data and develop common strategies against osteoporosis. Because in my country there is not enough support for research because it was not on the agenda and then when you look at the medical faculties, we don't have professors to teach it and to train our physicians and our nurses. So it's a Call to action today on the different levels, first to reach our citizens, but my personal commitment is really not only to reach the citizens, that's really important, NGOs are the best supporters of politicians, but to reach the politicians and to change their politics, because without health policy we can change very little and let me say, a lot has been done from the German Green Cross. Mrs Von Stakelberg and others and in this context I will mention the exhibition here in Lisbon where Oliviero Toscani it's really impressive when you go there, seeing women and men, different social situation, different age, and you look at their faces, you have the body and you have the faces and then you have really the human tragedy, but also the human strength and so as you said already, let us try to help them and to form our interest groups because my last phrase, sentences, Mel Read as a European Parliamentarian, really took the initiative and have report from the European Parliament with 24 parliamentarians. We should follow her example in our parliaments, going forward, forming these interest groups and as well on the national as well as on the regional level and I am convinced we will win the battle. You need knowledge, but only knowledge without conviction you can change nothing.

Thank you very much to have integrated and to have invited me in your group. Thank you.

Applause.

MEL READ

Rita, thank you that was inspirational and practical as even and I know that my German colleagues in the European Parliament will want to be supportive of things that are already happening in Germany. Thank you very much.

Now we're going to hear from Ann Richards, who is the former Governor of Texas and is an avid spokesperson for osteoporosis. I understand you have the early stages of the disease Ann and I know that you have a formidable track record talking to women and health care professionals, both in the United States of America and indeed all over the world. So Ann we look forward to your contribution.

Thanks.

ANN RICHARDS

Thank you very much Mel. I am always energised to be around a bunch of smart women. (Laughter). Its wonderful to hear you and that doesn't exclude you, Doctor. (Laughter). But this is my story.

Like some of the women at this table, I have a personal experience of osteoporosis. I shepherded my mother through her last illnesses and her death. Over about 5 years my mama just broke off into pieces. She broke her arm, she broke her wrist, she broke her hip and then her mental capacity began to go with all of the care given and all the various kinds of medications that went with the pain. And what have I learned from her dying? I learned that the decision to take care of yourself or not to take care of yourself affects the people you love as much as it affects you. I learned that early diagnosis and treatment can prevent the worst of the disease and can minimise its effects.

I first suspected something was changing with my own bones when my shirt collars didn't fit the same anymore. I thought perhaps it was something about the way they were making clothes now and that they had simply altered the way they were putting collars on. And then of course I realised finally that my neck was shrinking and as a consequence when I sat down my coat collar would rise up.

Well after mama was diagnosed I had bone density scans and of course learned that I had early stage osteoporosis. As a result, I take medication to help my bones and to strengthen my bones and muscles. I lift weight and I walk regularly, because weight-bearing exercise is one of the things that you can do to stabilise and build your bone density and I'm just hell in the gym. My trainers, who are those guys you know that, when I first walk in, always are a little taken aback at what they've taken on, but they get used to me and then they take a lot of pride in the fact that they're making a difference in my life. I take calcium and other supplements, fruits and vegetables comprise the majority of my diet. I eat a lot of fish and I don't even let them put fat foods on my plate because I don't want to trust my almost perfect willpower. I have seen the diets that are brought to you now in restaurants where before you might have a grilled chicken breast, it now is top of a pile of mashed potatoes, which you know is full of that wonderful tasting rich butter. So I make them take it back and bring it back with just the chicken, because I know some forks in my time that have darted out into those potatoes when I wasn't watching.

The message is that I am determined to make my body strong, and I am determined to spread the message as much as I possibly can that you

can take charge of your own health. We accept too many hardships as a natural part of ageing and we are uninformed about what we can do to help ourselves.

Studies in my country show that women are rarely counselled about osteoporosis until they have the disease or until worse as you've all said, until they've had their first fracture. In my own case, even though I had broken a hand, I'd broken an ankle, I had to ask my doctor for a bone density test. I know that in many other countries its not only practice, it is a Government policy to withhold testing and treatment until after the first fracture. The previous speakers have already discussed the price we pay for the failure to diagnose and to treat early.

Right now the European Community spends about 4-5 billion euros every year for hospital health care related osteoporosis and that figure represents a 33% increase over the last three years. In the United States, we spend \$17 billion a year treating osteoporosis and the injuries that it produces and if we do not act that figure is going to increase to \$60 billion over the next 20 years. It's absolutely ridiculous. But the truly tragic cost is in the lives of women and men who could have avoided the disease or the worst of it and the families who suffered with them through prevention and early diagnosis. We can save our medical systems hundreds of millions of dollars in treatment costs and we can eliminate needless suffering.

We don't have to die the way our mothers did and I am living proof. Last summer I was in New York. I was walking down Madison Avenue and the next thing I knew I had tripped over a piece of plywood and fallen literally flat on my face. It took twenty stitches and some surgery later to improve the mobility of my eyebrow, but here's the message in this, I did not break a bone and I know that I would have without medication, a good diet and exercise. I know that I would have broken a bone if I had not started the regime of taking care of myself that I did. I am 68 years old. I have never felt better or stronger in my life and I know it is a cliché but it is God's truth "if I can you can".

The good news is that we all get well and I expect nothing less for myself and my daughters and my granddaughters and I hope that by signing this agreement today, this Call to Action, that we will accept nothing less for all the women, all over the world.

Thank you.

Applause

MEL READ

Ann, thank you, thank you for sharing your practical experience in taking care of your own health and the challenge for each of us to take care of our health, it was a joy to listen to you and we wish you well personally.

Colleagues we've seen and heard how serious osteoporosis is. We've seen the considerable human costs and the economic costs. And that osteoporosis results in more disability than many other diseases such as strokes, heart attacks and breast cancer. We've highlighted the major challenges we've posed today with restricted availability of diagnosis and of proven therapies, until after the first fracture in countries such as Australia and France. That to date osteoporosis has not received the attention it deserves by policy makers. That the osteoporosis movement is about a decade behind the achievements of the breast cancer movement. We've heard how we must take responsibility for our own health and we've discussed what a difference advocacy can make and how today's collective call for action can be used pragmatically within a country such as Canada to change osteoporosis policy now. And that, colleagues brings us to the purpose of today's meeting. To announce our Call to Action, which builds on and geographically expands the Call to Action announced by the European Parliament's Osteoporosis Interest Group at the end of last year.

We, the Patrons and Members of the Women Leaders Roundtable and the International Osteoporosis Foundation, urge policy makers around the world to make the diagnosis and treatment of osteoporosis a priority on public health agendas by taking the following actions.

To pay for and improve access to bone density scans for people with osteoporosis risk factors before the first fracture and to pay for proven therapies for people with osteoporosis before the first fracture.

We the Patrons and Members of the Women Leaders Roundtable will act as osteoporosis ambassadors in our own countries and our own regions to strongly support these changes and we urge women, physicians and all concerned people around the world to help us bring about these changes.

We are going re-convene in two years to monitor progress and I very much hope that's an optimistic occasion.

Colleagues, today osteoporosis can be easily prevented and effectively treated. We call upon Government leaders and policy makers around the world to act now to improve access to diagnosis and therapies and

thereby improving the lives of millions of women today and ensuring a better future for millions more.

Our Call to Action is now going to be signed by the Patrons and Members of the roundtable.

(Silence while signing taking place).

Colleagues, colleagues, we are almost at the finish of our afternoon. I would like to thank my colleagues for their support, to thank the International Osteoporosis for organising this very important initiative and thanks to Eli Lilly for providing an unrestricted Educational Grant to make this event possible.

Colleagues this concludes the formal part of our meeting. Journalists will shortly have the opportunity to ask questions and interview individual roundtable members in here and refreshments will be served to you just outside the auditorium. But could I ask the audience, including the journalists to kindly stay in the auditorium until the roundtable patrons and members have been escorted out.

We'll meet most of you a little bit later.

Thank you very much indeed. Thank you.

Applause.