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## **HM Queen Rania of Jordan leads international group of women dignitaries to call on policymakers to provide greater access to diagnosis and treatment of osteoporosis**

*Eleven international women leaders urge policymakers to end suffering and curb the economic burden caused by delaying osteoporosis diagnosis and treatment until after the first bone fracture*

Her Majesty Queen Rania of Jordan led a group of high profile women from around the world today to urge policymakers to improve access to diagnosis and treatment of osteoporosis before the first bone fracture.

Eleven international women leaders took part in the first gathering of the International Osteoporosis Foundation's (IOF) Women Leaders' Roundtable, a panel of distinguished women committed to finding ways to improve access to osteoporosis diagnosis and treatment.

Osteoporosis touches one in three women over the age of 50 causing pain, disability, loss of independence and even death. It is a debilitating disease that affects an estimated 150 million people <sup>1</sup>.

The group noted that despite the economic burden associated with treating fractures, many patients do not have access to diagnostic tests and treatment until after they have suffered a fracture, leaving them more susceptible to further broken bones, leading to increased disability and requiring expensive hospitalization and rehabilitation.

"Although we have effective treatments for osteoporosis, each year millions of our grandmothers are crippled and disfigured because they don't have easy and sufficient access to diagnosis and medication", said Her Majesty Queen Rania. "The women who have cared for us now need us to care enough to urge policymakers to give them access to proven therapies before they break a bone. Today, I join with women across the world to care for an end to this unnecessary suffering."

Currently, even in developed countries such as Ireland and France, access to therapies proven to be effective in reducing the risk of fracture is limited only to those who have suffered fractures<sup>2,3</sup>. Also, in many countries bone density tests (commonly called DXA scans) are not reimbursed. In other countries, the equipment to perform the test is limited or not used to full capacity, resulting in waits of six months up to one year<sup>3</sup>.

In a Call to Action, signed during today's meeting, the roundtable members urged policy makers to make osteoporosis a priority on national health care agendas, specifically asking them to:

- Pay for and improve availability of bone density scans for women with osteoporosis risk factors **before** the first fracture.
- Pay for therapies proven to prevent fractures for women with osteoporosis, prior to the first fracture, critical juncture in disease development.

### **Preventing the 'fracture cascade'**

"It's crucial that we diagnose and treat women before they have a fracture," said Professor Pierre D. Delmas, president of the International Osteoporosis Foundation. "If we don't, it's often only a matter of time before we see a 'fracture cascade' – the patient suffers a second, third, even fourth fracture, experiences significant pain and becomes debilitated and demoralized. We can stop this from happening if governments allow us to diagnose and effectively treat during the early stages of the disease."<sup>4</sup>

Within the first year after suffering a spinal fracture, one in five women will experience an additional fracture, suggesting it can be a quickly devastating disease once a fracture occurs. Studies have shown that each additional fracture is associated with an additional significant increase in functional limitation, disability and back pain.<sup>5</sup>

Today, osteoporosis affects one in three women over the age of 50, causing pain, disability, loss of independence and even death.<sup>6</sup> Osteoporosis results from a slowing in the development of new bone tissue, which leaves bones porous and fragile. The disease escalates in response to dropping levels of oestrogen, which occurs with menopause.<sup>7</sup>

### **The costs of not treating early**

Currently, the IOF estimates the annual direct cost of treating osteoporosis fractures in Europe and the United States is US\$ 27 billion (€30 billion)<sup>8</sup>. That cost is expected to grow dramatically in coming years as the world population grows and ages.

"While some governments restrict access to diagnosis and treatment to save money, they're not considering the high cost of treating women after they fracture. Much of these costs for hospitalization could be avoided if governments would allow women access to earlier diagnosis and effective treatment," said Imelda Read, member of the European Parliament and chair of the European Parliament Osteoporosis Interest Group, which

issued a similar "Call to Action" at the December, 2001 launch in Brussels of the IOF policy audit report "Osteoporosis in the European Community". "Providing that access would be a true investment, both in financial and human terms."

The Roundtable will reconvene in two years to monitor progress. In the interim, the patrons and members of the IOF Women Leaders' Roundtable will act as osteoporosis ambassadors in their respective countries and strongly support specific initiatives to change diagnosis and treatment policy.

Roundtable patrons:

- Her Majesty Queen Rania of Jordan, patron of the International Osteoporosis Foundation
- Mrs Nazek Rafic Hariri, president of IOF's 206: A Bone Fund
- Mrs Camilla Parker Bowles, president of the UK National Osteoporosis

Roundtable members:

- Maxine McKew, award winning journalist, political and social affairs television reporter and patron of Osteoporosis **Australia**
- Regina Prado, osteoporosis patient and advocate, **Brazil**
- Maureen McTeer, medical law specialist and author, spokesperson, Osteoporosis Society of **Canada**
- Ritua Süssmuth, member of Parliament, former president of the Bundestag, **Germany**
- Imelda Read, member of the European Parliament (MEP), chair of the European Parliament Osteoporosis Interest Group, **European Union**
- Anna Molinari, fashion designer, osteoporosis advocate, **Italy**
- Maria Elisa Domingues, member of Parliament, **Portugal**
- Ann Richards, former governor, Texas, and osteoporosis spokesperson, **USA**

### **Mrs. Nazek Hariri named First IOF Ambassador**

On this occasion, Mrs. Nazek Hariri, president of IOF's 206: A Bone Fund and a patron of the Roundtable, was named First IOF Ambassador. Mrs. Hariri was honoured by IOF for her outstanding contribution to the foundation's work and the cause of osteoporosis.

The Roundtable was supported by an unrestricted educational grant from Eli Lilly and Company.

### **Notes to editors**

1. Hall M. Target Osteoporosis. ABPI, London, 1998
2. Summary Report on Osteoporosis in the European Community – Action for Prevention (c) European Communities/European Foundation for Osteoporosis (now IOF), 1998
3. Osteoporosis in the European Community: A Call to Action, an audit of policy developments since 1998, International Osteoporosis Foundation, December, 2001

4. Lindsay, JAMA, 2001
  5. Nevitt MC et al. Association of Radiographically Detected Vertebral Fractures with Back Pain and Function: A Prospective study. *Annals of Internal Medicine*. Vol 128; 10: 793-800
  6. International Osteoporosis Foundation
  7. International Osteoporosis Foundation Annual Report 1998
  8. International Osteoporosis Foundation. 1998 World Osteoporosis Day information
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