

# OsteoLink

OsteoLink is the first online and in-person social network in Europe and Australia designed for people with osteoporosis, their friends, families and healthcare professionals. OsteoLink operates globally but is implemented locally, working with a network of IOF member Societies, who ensure the local social and support needs of patients, their families and their related healthcare professionals are taken into account.

- A report, launched in June 2011 by the IOF in collaboration with EFPIA, concludes that in Europe's five largest countries and Sweden, an estimated 2.5 million new fragility fractures occurred in 2010 – the equivalent of 280 fractures per hour. The report also shows that 80 deaths per day are attributable to fragility fractures. Despite the availability of treatment and patients' increased awareness of risk, treatment adherence is low, leading to an increased risk of fracture and decreased quality of life. Underpinning the OsteoLink programme is the 2009 IOF Survey 'The Gaps Between Patient and Physician Understanding of the Emotional and Physician Impact of Osteoporosis' (*Arch Osteoporos 2010;5:145-153*), which highlighted unmet needs in communications between osteoporosis patients and health professionals. OsteoLink is a direct response to this need.

- The target groups of users are patients, families and healthcare professionals. The clinical outcome of osteoporosis is fracture which results in a downward spiral for patients including fear of fracture, isolation, lack of control over life. The result for the family is managing the suffering of the patient as well as patient care. Healthcare professionals are aware that they rarely have adequate time to provide all of the information and support needed by the patients. Another target group for OsteoLink is payers. There is convincing evidence that prevention of fractures in high-risk individuals is more cost-effective than fracture treatment, and this needs to be explained clearly to payers on the basis of the compelling data. - It is well established that the over-55s, where osteoporosis has the highest incidence, are the fastest growing group of internet users. With an ageing population in Europe together with tightened health budgets, there is enormous potential for OsteoLink to play an increasing role in the support and education of people with osteoporosis. - The technology used for OsteoLink is not novel, but its application and approach are unique, as the highly adaptable and flexible master social networking site is adapted at a country level, translated into a local language, implemented by a local society concerned with patients with osteoporosis and supported by a global and local scientific committee. OsteoLink is easily replicated at a country level and has potential for economic exploitation given the captive audience with specific needs. - OsteoLink is now live in Sweden, Austria, Switzerland and Australia. It is scheduled to go live in Germany and Greece. Negotiations with Portugal, France and Spain have started, and many more



countries have expressed an interest in the programme. - As of December 2011, the total number of OsteoLink members was 454, with the total number of unique OsteoLink users being 8,198. Austria had 2,578 unique visitors, with almost 30% of visitors returning more than 15 times suggesting a higher than average quality of experience. Sweden had 2,697 unique visitors and received over 39,441 page views. Switzerland launched in October 2011 and had already seen 275 unique visitors by the end of 2011. In addition, Australia, as the first English-speaking OsteoLink website had an encouraging start following its launch in November 2011. -Time to market for a local society with funding in place is 9 months. Potential barriers to success are as follows: lack of funding; more than one National Society might incite low level of collaboration and engagement of users; lack of comfort with the internet of potential users at the country level; effectiveness of local marketing and engagement efforts