

## **Potential advantages and disadvantages of bone mineral density surveillance for childhood, adolescent and young adult cancer survivors – A Survivor Information Brochure**

### **Why should I be aware of the risk of low bone mineral density (weak bones)?**

- Bone mineral density is an important determinant of bone strength. This means that if you have low bone mineral density (weak bones), you probably break your bones more easily.
- Having weak bones around the age of 25 (when your bones should be the heaviest) predicts for osteoporosis and bone fractures later in life.
- As a survivor of childhood, adolescent or young adult cancer you may have a higher risk of developing weak bones compared to people of similar age in the general population.
- If your brain and spinal cord were exposed to radiation as part of your treatment for a childhood, adolescent, or young adult cancer (cranial[spinal] irradiation), or if you were treated with total body irradiation, you have an increased risk of developing weak bones.
- If you were treated with corticosteroids (as anti-cancer treatment) you may have an increased risk of weak bones as well. However, it is unclear if corticosteroids can lead to weak bones in the long term.
- While some people treated with cranial(spinal) irradiation, total body irradiation, and/or corticosteroids will develop weak bones at a young age, most will not.
- However, among those who develop weak bones, detecting it early can possibly prevent bone fractures and may therefore reduce consequences such as pain, surgery, and temporary immobilization.
- It is possible to detect weak bones early by having bone mineral density screening, but bone mineral density screening has advantages and disadvantages.
- This information sheet can be used to help you and your healthcare provider decide if having bone mineral density screening is the right choice for you.

### **What is bone mineral density screening?**

- Bone mineral density screening is performed with a bone scan that uses low dose X-rays to see how strong your bones are.

### **What are the potential advantages of having bone mineral density screening?**

- You may feel reassured if you have normal bone mineral density at this time. However, weak bones may still develop in the future, and your fracture risk may still be increased due to other reasons.
- Early detection would allow doctors to monitor the bone mineral density course over time. In addition, early detection would allow referral to a specialized bone doctor who can further evaluate your bone health, which may both help to determine if/when treatment is needed.
- You may be more likely to have weak bones detected at an earlier time point when certain interventions may be most effective (before the end of puberty), and as a result, bone fractures may be prevented.

### **What are the potential disadvantages of having bone mineral density screening?**

- You may experience anxiety and stress about having bone mineral density screening and what the test results will show.
- You may feel more like a patient rather than a healthy survivor if you decide to have bone mineral density screening.

- You may be incorrectly diagnosed with weak bones (misdiagnosis), or diagnosed with weak bones that never would have caused fractures (overdiagnosis), although your doctor carefully considers treatment.
- We do not know if early treatment of weak bones leads to better health (no further weakening of the bones or prevention of fractures) in childhood, adolescent and young adult cancer survivors. However, in the general population, we know that this is the case.
- The diagnosis of weak bones may affect your ability to obtain healthcare and/or life insurance.

#### **What are the potential disadvantages associated with this bone scan?**

- This bone scan is associated with potential harms from radiation exposure (especially in the context of cumulative radiation dose after cancer treatment), although the dose of one scan is considered negligible (less than one chest X-ray or a short flight).
- This bone scan may be costly and may not be covered by your health insurance. However, your healthcare provider could write a letter of medical necessity to explain that you are at increased risk of weak bones and why you may benefit from a bone scan.

#### **What are the international screening recommendations?**

- If you were treated with radiotherapy to your brain or spinal cord, total body irradiation, and/or corticosteroids, it is important that you are aware of the risk of weak bones, and pay specific attention to their possible consequences (acute back pain, [spinal] fractures, and loss of height due to spinal fractures).
- If you were treated with radiotherapy to your brain or spinal cord, bone mineral density screening is recommended at entry into long-term follow-up (beginning two or more years following completion of therapy) and at 25 years of age.
- If you were treated with total body irradiation, bone mineral density screening is reasonable at entry into long-term follow-up and at 25 years of age.
- If you were treated with corticosteroids as anti-cancer treatment, we cannot recommend for or against routine bone mineral density screening because we do not know if your health outcomes will be better if we detect weak bones early. It is important that you make the decision whether or not to screen together with your healthcare providers, oncology and survivorship team, and individual support networks. Careful consideration of the potential advantages and disadvantages is advised.

*Thank you for taking the time to read this information sheet. If you have any questions regarding the information included in this brochure or if you require emotional support and advice regarding your thoughts and feelings, please contact your healthcare provider for advice and support.*

#### **Publication**

van Atteveld JE, Mulder RL, van den Heuvel-Eibrink MM, Hudson MM, Kremer LCM, Skinner R, Wallace WH, Constone LS, Higham CE, Kaste SC, Niinimäki R, Mostoufi-Moab S, Alos N, Fintini D, Templeton KJ, Ward LM, Frey E, Franceschi R, Pavasovic V, Karol SE, Amin NL, Vrooman LM, Harila-Saari A, Demoor-Goldschmidt C, Murray RD, Bardi E, Lequin MH, Faienza MF, Zaikova O, Berger C, Mora S, Ness KK, Neggers SJCM, Pluijms SMF, Simmons JH, Di Iorgi N. Bone mineral density surveillance for childhood, adolescent, and young adult cancer survivors: evidence-based recommendations from the International Late Effects of Childhood Cancer Guideline Harmonization Group. *Lancet Diabetes Endocrinol* 2021;9:622-637.