

## **ESPE Patient Information on COVID-19 and Pediatric Endocrine Diseases**

### **Disease specific information and advice: RARE BONE DISEASES**

The COVID-19 pandemic has impacted on the care of children and adolescents worldwide. Emerging evidence continues to educate the paediatric community on the actions required to protect our communities. This information is based on the published knowledge available up to September 2020. The Rare Bone Disease paediatric community comprise children and adolescents with a large number of diverse and heterogenous conditions. This advice is intended to provide generic advice only. Please contact your healthcare professional if you have specific concerns that are not addressed by this leaflet.

#### **Sources of information:**

Patient information medical advisory boards have endeavoured to provide up to date medical evidence for families affected with specialist conditions. This leaflet has been drafted with advice also listed on the following websites.

ERN-BOND – the European Reference Network for Rare Bone Diseases.

Brittle Bone UK

OIFE – Osteogenesis imperfecta Federation Europe.

#### **Are children with Rare Bone Diseases at increased risk of COVID-19 infection?**

There is no evidence suggesting that children with rare bone disease or bone fragility are at increased risk of COVID-19 infection in comparison to the general population.<sup>1,2</sup>

#### **Are children with Rare Bone Diseases at increased risk of a more severe illness due to COVID-19?**

While there is no evidence that children are at increased risk of severe illness due to COVID-19, there is evidence that those with underlying cardiac and pulmonary conditions have more severe outcomes due to influenza, parainfluenza and non-COVID-19 coronavirus.<sup>2</sup> There is extrapolated data from adults that those with reduced pulmonary function due to kyphoscoliosis are also more susceptible to severe infection.<sup>3</sup>

The rigidity of the chest wall in bone fragility conditions due to recurrent fractures and small thoracic cavity size could lead to difficulties with ventilation in those affected severely by COVID-19 infection.

#### **Should children with Rare Bone disease take greater precautions compared to the general population?**

In general, children and adolescents with Rare Bone diseases do not need to take additional precautions. However, those with complications of Rare Bone Diseases should be protected from infection if community transmission of COVID-19 is evident in the geographical area. This applies particularly to those with underlying cardiac or pulmonary disease or severe kyphoscoliosis, which compromises pulmonary function, children with central or obstructive apnoea or those with immature lung function due to restrictive disease e.g. in severe osteogenesis imperfecta requiring ventilator support

**Do the quarantine measures for patients with Rare Bone diseases differ from the general population?**

No, there is no reason for quarantine measures to vary. Prolonged isolation or restrictions in exercise are not advocated for children with rare bone disease as the positive effects of activity and sunlight on bone health far outweigh the risk of transmission outdoors. Children with rare bone diseases are known to be resilient in the face of adversity but psychological well-being and peer interaction are vital to tolerating the long-term effects of a pandemic.

**Should Children and Adolescents with Rare Bone Diseases discontinue any medications or treatment during the COVID-19 pandemic?**

Continuation of medications used in the care of rare bone disease is vital, particularly as many children and adolescents are engaged in the study of novel therapies or newer drugs which require close monitoring.

Vitamin D supplementation with calcium is considered a standard of care in metabolic bone disease. In addition, there is evidence to suggest that Vitamin D protects against acute respiratory tract infection favouring the innate and adaptive immunological response. Vitamin D also reduces circulating IL6 in critically ill patients. A reduction in exposure to sunlight due to limitations in physical activity can result in vitamin D insufficiency so those with rare bone disease should be encouraged to optimise dietary intake or supplementation of Vitamin D if their sunlight exposure is reduced or if they are known to have Vitamin D insufficiency. Optimising vitamin D status to recommendations by national and international public health agencies will certainly have benefits for bone health and potential benefits for Covid-19.<sup>4</sup>

Children on aminobisphosphonate infusions e.g. pamidronate or zoledronate can tolerate a delay in their infusion protocol to ameliorate the risk of attending hospital during periods of high community transmission. However, if a safe environment is available then there is no reason to defer care.

The National Institute for Clinical Excellence [NICE] in the United Kingdom has advocated that Denosumab should be continued without delay while Zoledronate can be delayed for up to six months.<sup>5</sup>

**Should my child be expected to attend my hospital appointments during the COVID-19 pandemic?**

Medical teams have put many measures in place to cope with the pandemic. Telemedicine has expanded rapidly enabling specialist teams to engage with patients and their families by phone, videolink, e-mail or social media.

Families are encouraged to stay in regular telephone contact with the specialist teams to ensure that prescriptions are up to date, concerns regarding stocks of medicine are addressed appropriately and biochemical monitoring for optimum care can be arranged.

### **Summary:**

Children and Adolescents with Rare Bone Diseases are encouraged to pursue a balanced lifestyle with adequate physical activity, sunlight exposure and peer interaction while following the established COVID-19 guidelines aimed at reducing disease transmission.

### **References:**

1. Providing high-quality care remotely to patients with rare bone diseases during COVID-19 pandemic Brizola et al. Orphanet Journal of Rare Diseases (2020) 15:228
2. Multicenter initial guidance on use of antivirals for children with COVID-19/SARS-CoV-2. Chiotos et al. J Pediatric Infect Dis Soc 2020 Apr 22
3. Management of patients with neuromuscular disorders at the time of the SARS-CoV-2 pandemic. Costamagna et al. [J Neurol](#). 2020 Aug 17 : 1–1
4. Vitamin D and Inflammation: Potential Implications for Severity of Covid-19. Laired et al. Ir Med J 2020 May 7;113(5):81.
5. <https://www.nice.org.uk/guidance/ng167/chapter/4-Treatment-considerations>