



**Rare Bone Disease Advocacy Alliance  
Draft Fiscal Year 2015 Report Language  
Labor, Health & Human Services, and Education Appropriations  
Department of Health & Human Services  
Office of the Director**

*Rare Bone Disease Research* – The Committee is concerned by the impact of rare bone diseases and the painful, debilitating complications that are often exacerbated by related respiratory, coronary circulatory, pulmonary and other body system complications. The Committee believes that there is a serious lack of sufficient government-sponsored research in this field and urges the Director to work with all relevant institutes to enhance and accelerate interdisciplinary research leading to a better understanding of the diseases, to encourage the development of effective treatments to ultimately improve the health of individuals with rare bone diseases, including: Fibrous Dysplasia, Fibrodysplasia Ossificans Progressiva, Gorham’s Disease, Lymphangiomatosis, Hypophosphatasia, X-Linked Hypophosphatemia, Multiple Hereditary Exostoses, Melhoreostosis, Osteogenesis Imperfecta, and Osteopetrosis.