

IRB No.: 0359/ Ame00006499

Approval Date: 3/5/2009

Expiration Date: 2/28/2010

Dear Patient and Family,

The International Skeletal Dysplasia Registry is a longstanding international referral center that has been involved in providing clinical diagnosis, patient care, as well as collecting data on individuals and families with abnormalities of the bones. To aid in establishing a correct diagnosis for these relatively rare genetic disorders, physicians send us clinical information and radiographs (x-rays). In some instances, additional materials such as blood or tissue samples are also sent. In addition to our role in clinical diagnosis, we are also very interested in performing research focused on skeletal disorders. Research is done in the clinic by defining the features of these disorders, and in the laboratory by identifying the causes of these conditions. This research educates patient caretakers and leads to a better understanding of the disorders, all of which benefit patients.

Your physician has sent us clinical records, x-rays and perhaps other material for us to help in reaching a clinical diagnosis for you or a family member. We would like to obtain your permission to include your x-rays, clinical records and samples in our research. All x-rays, clinical records and samples will be retained indefinitely by the Registry.

You or your family members are being asked to participate in research that will assist in defining the clinical features, cause and possible treatment of skeletal disorders. Your participation in this study is completely voluntary. Whether or not you elect to participate will not affect the clinical service your family receives from either the Cedars-Sinai - Medical Genetics – Birth Defects Center or the International Skeletal Dysplasia Registry.

We would like to contact you by telephone to discuss this consent process further and answer any questions you may have. Please either complete the bottom of this letter and return it by fax or by mail, or call us at **1-800-656-1909** or **(310) 423-9915**. We look forward to hearing from you.

Sincerely,

The International Skeletal Dysplasia Registry

Name of Person Completing this Form: _____

Relationship to patient: _____

Patient's name: _____ **Date of Birth:** _____

Address: _____

City: _____ **State:** _____ **Zip Code:** _____

Contact Telephone: (day): _____ **(evening):** _____

Fax to: (310) 423-0462

Mail to: Arleen Hernandez

International Skeletal Dysplasia Registry

Cedars-Sinai Medical Center

8700 Beverly Blvd., Suite 665W

Los Angeles, CA 90048

This address is for the U.S. Postal Service ONLY and should not be used if shipping by a courier service.