



**International Skeletal Dysplasia Registry
Instructions for Submission of Prenatal Ultrasounds for Research**

Prenatal ultrasounds may ONLY be submitted to the Registry for review under our research protocol. This is a 2-step process that requires:

- 1) Submission of prenatal material
- 2) Submission of post-delivery materials on the fetus or baby including x-rays, cord blood, and fetal tissue specimens if applicable. The patient must consent to both the review of the ultrasound, parental blood samples, and submission of follow up materials on the fetus at the time that the case is first submitted to the Registry. The referring center must agree to aid in the collection of material that is needed for final diagnosis.

**** We do not provide a clinical consultation service for review of ultrasounds ****

Please note that review of the prenatal ultrasound offers a preliminary differential diagnosis on a research basis. Our findings will only be reported directly to the referring MD and the genetic counselor. Contact information must be sent for both individuals. Final diagnosis is made post-delivery via radiographs.

The following materials are required for prenatal ultrasound submission and review:

1. **Completed Patient Contact Form** - A genetic counselor or investigator from the Registry will contact your patient and review the consenting process.
2. **Completed Consent Forms** - The patient and the baby's father will need to each sign their own individual consent forms and a third consent form will need to be completed with the baby listed as the research subject. Please provide a copy of our consent forms to your patient to take home and review. Consent forms are found under the [Forms](#) tab on our website.
3. **Most Recent Ultrasound Images**

Total spine	Clavicle and length
All long bone measurements	Foot and length
All ultrasound parameters	Hands
Profile of the face	Chest
Scapulae	
4. **Most Recent Ultrasound Reports**
5. **Post-delivery or Post-termination Follow-Up Materials**
 - a. Radiographs (Required)
 - b. Cord Blood
 - c. Tissue Specimens when appropriate: Femurs (including the femoral head); 3 ribs (including costochondral junction), and a skin sample. ALL specimens should be sent in a sterile container in sterile tissue culture medium on wet ice or cold packs.

Shipping Address: International Skeletal Dysplasia Registry
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