

**Boler-Parseghian Center for Rare and Neglected Diseases
Natural History Study**

Greetings from the Boler-Parseghian Center for Rare and Neglected Diseases (CRND) at the University of Notre Dame!

We train advanced pre-medical students and fellows to assess medical records to assist physicians, researchers, and patient families in developing natural histories for rare diseases. They learn how to analyze your records to identify important clinical symptoms, determine their severity and summarize how they change over time. This helps develop treatment strategies. They are also trained to obtain the latest information on what is known about the rare disease and available therapies. By participating, we will assess your (or your family member's) medical record and return to you a password protected electronic copy of your record.

If you are interested in participating, we ask that you sign and return this consent form to allow us to speak to you and view your medical records. Any information that we gather will be de-identified and entered into a database with de-identified information from other records. This study will help physicians and researchers improve disease management, early diagnosis and accelerate therapeutic research.

With your participation, we can assist you with finding resources for your disease. We can help identify and approach physicians, clinical centers, support groups, explore current research and find available resources for your disease. Please feel free to contact us through email or phone.

Best Wishes,

Barbara Calhoun

Barbara Calhoun, MSN, RN, PNP

Kasturi Haldar

Kasturi Haldar, PhD, Director

Patient Name: _____ **Parent/Guardian:** _____

I give my permission for medical records to be viewed by the following people (check all that apply):

- Students at the University of Notre Dame: students will assess de-identified records
 Physicians: Physicians will use this information to improve disease management protocols
 Researchers: Researchers will use this information to develop new therapeutics

Signature

Date

Address

Email

Phone Number

Please email PDF copy of form to bcalhoun@nd.edu and send hard copy to 193 Galvin Life Sciences Center, Notre Dame, IN 46556