

JOIN THE HYPOPHOSPHATASIA MOVEMENT

Announcing the Launch of the
CoRDS Soft Bones International
Hypophosphatasia Registry

Soft Bones partnered with the Coordination of Rare Diseases at Sanford (CoRDS) to host a patient registry for individuals diagnosed with hypophosphatasia (HPP) and carriers of the disease.

This information provides a secure way for patients to make their basic disease information available to researchers without sacrificing privacy.

Participation is voluntary and those who enroll may withdraw at any time.



WHO:

Anyone diagnosed with any type of HPP or those who are carriers, undiagnosed or suspect they may have the metabolic bone disease



HOW:

To enroll in the registry, visit www.sanfordresearch.org/cordsregistryform fill out the form, and specify that you are interested in joining the disease-specific Soft Bones International Hypophosphatasia Registry.



Enroll online:

1. Complete the Initial Screening Form. When filling out the diagnosis, simply enter “hypophosphatasia” and select the correct diagnosis, from the list, to the best of your ability. You can always go back in and make updates.
2. Complete the Log In Setup Page. Your username will be displayed and you will be asked to create a password. NOTE: Once your login is complete, you will receive two emails – one with your username and the other with your password. There is no need to access these emails, at this point, rather they should be saved for your records.
3. Complete the CoRDS Standard Questionnaire.
4. Complete the Soft Bones Questionnaire. Remember to select the “Share with Soft Bones Foundation” option before submitting.



Enroll by mail:

1. Complete the Initial Screening Form - indicate that you prefer to enroll by mail.
2. CoRDS will send the enrollment forms in the mail. Completing the forms takes approximately 20 minutes. You will not be fully enrolled in the registry until you have completed AND returned the forms. NOTE: Participants who enroll by mail but wish to switch to online, can do so by contacting CoRDS.

NOTE: Mobile phones and tablets are not supported for online enrollment at this time. For any technical issues, please contact CoRDS

For more information:

About CoRDS

Visit: www.sanfordresearch.org/cords

Email: cords@sanfordhealth.org

Call: (877) 658-9192

About Soft Bones

Visit: www.SoftBones.org

Email: info@softbones.org

Call: (866) 827-9937



Soft Bones will not have access to names or any information that allows us to identify individuals associated with the data.