

Physical function and disease impact evaluation tool

For physicians treating children

Children with hypophosphatasia (HPP) and their parents and caregivers may not fully realize all of the ways in which HPP is affecting the child's physical function and quality of life. They may also be unaware that certain signs or symptoms could actually be caused by HPP. The following questions may help uncover the full extent of their functional limitations and disease impact.



Mobility impairments

Impairment?

Symptoms worsened over time?

Does your child's HPP limit his/her ability to get around (eg, difficulty walking to school, riding a bike)?



Difficulty with normal childhood activities

How does your child's ability to sleep, dress, and feed him/herself compare with other children of similar age?

Have you had to adjust your daily routines to accommodate your child's symptoms of HPP (eg, getting up earlier, leaving or skipping activities)? Does your child find it difficult to walk, go up or down stairs, or stand from a sitting position?

After participating in normal childhood activities, does your child experience pain or unusual fatigue? Does he/she need to rest for extended periods, take pain medication, and/or use ice packs?



Inability to participate fully in normal childhood recreational activities

Are you concerned about your child's physical activity/fitness level relative to other children his/her age?

Are there activities your child cannot participate in or that will later cause discomfort, pain, and/or unusual fatigue? What activities does your child engage in during recess/gym class/free time?



Problems at school

Has your child's school attendance or grades suffered because of symptoms of HPP or medical needs?

Has your child had social issues at school (eg, bullying, difficulty making friends, being chosen last for games at recess/gym, not invited to birthday parties or sleepovers)?



Limited ability to participate in normal family and social life

Does your child have difficulty keeping up with his/her friends?

Do symptoms of HPP limit your child's ability to participate in certain types of family/social activities (eg, active birthday parties, visiting theme parks)?

Physical function and disease impact evaluation tool

For physicians treating adults

Patients with HPP and their caregivers may not fully realize all of the ways in which HPP is affecting their physical function and quality of life. They may also be unaware that certain signs or symptoms could actually be caused by HPP. The following questions may help uncover the full extent of their functional limitations and disease impact.



Mobility impairments

Impairment? Symptoms worsened over time?

Has your HPP affected your ability to get around? Do you have difficulty driving, walking, or using public transportation?



Pain and muscle weakness

Do you have pain? How would you describe this pain? How long have you had it? How often do you feel this pain or discomfort? Is it in a specific location or is it difficult to pinpoint the source? Do you need to use pain medication? What type and how often?

Does your bone, joint, or muscle pain and/or muscle weakness limit your choice of activities?

Difficulty with normal activities of daily living



Have you had to adjust your daily routine to accommodate your symptoms of HPP (eg, getting up earlier, changing your commute to work)?

Are there household activities (eg, cleaning, gardening, mowing the lawn, cooking, grocery shopping) that you previously did but are no longer able to do because of pain, weakness, fatigue, or other limitations?



Inability to maintain physical fitness

Are there any activities that you previously enjoyed but can no longer participate in due to reduced mobility, speed, or agility, and/or excessive pain/fatigue afterward?



Difficulty with employment

Have you ever missed an extended period of work or needed to take disability leave (short or long term) because of your HPP (eg, fractures, surgeries)?

Limited ability to participate in normal family and social life



Do your symptoms of HPP limit your ability to participate in certain types of family/social activities (eg, hosting holiday gatherings, playing/coaching sports, hiking, sightseeing, visiting theme parks)?

Do you ever feel anxious or depressed?