Hypophosphatasia Impact Patient Survey (HIPS) – English

Today’s Date _______ / _______/ _______
    Month  Day  Year

Person Completing Questionnaire

_____ Patient  _____ Parent/ Guardian or Caregiver of Patient  _____ Other

If you are not the patient, please complete the remainder of the questionnaire by providing information about the person who has been diagnosed with hypophosphatasia.

Gender  _____ Male  _____ Female
Current Age  _____ years
Country of Residence:

1. In general, would you say your child’s health is:
   
   ![Select one health rating]

2. During the past 4 weeks, has your child been limited in any of the following activities due to HEALTH problems?

   ![Select one limitation rating]

   a. Doing things that take some energy such as riding a bike or skating?
   ![Select one limitation rating]

   b. Bending, lifting, or stooping?
   ![Select one limitation rating]

3. During the past 4 weeks, has your child been limited in the KIND of schoolwork or activities with friends he/she could do because of PHYSICAL health problems?

   ![Select one limitation rating]

4. During the past 4 weeks, has your child been limited in the KIND of schoolwork or activities with friends he/she could do because of EMOTIONAL or BEHAVIORAL problems?

   ![Select one limitation rating]

5. During the past 4 weeks, how much bodily pain or discomfort has your child had?

   ![Select one pain rating]

6. During the past 4 weeks, how satisfied do you think your child has felt about his/her friendships?

   ![Select one satisfaction rating]
7. During the past 4 weeks, how satisfied do you think your child has felt about his/her life overall?

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Somewhat satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Very dissatisfied</th>
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8. During the past 4 weeks, how much of the time do you think your child acted bothered or upset?

<table>
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<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
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9. Compared to other children your child’s age, in general would you say his/her behavior is:

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<th>Excellent</th>
<th>Very good</th>
<th>Good</th>
<th>Fair</th>
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Current Height  _____ feet _____ inches OR  _____ centimeters

Current Weight  _____ pounds OR  _____ kilograms

Do other members of your family have hypophosphatasia?  _____ YES  _____ NO

If yes, how many of your relatives have been diagnosed with hypophosphatasia?  _____

At what age did you first experience symptoms of hypophosphatasia?  _____ Years

What were the first symptoms of hypophosphatasia that you experienced?

____________________________________________________________________________________________

MEDICAL HISTORY

Have you ever been diagnosed with or treated for any of the following conditions? (Check all that apply)

**Developmental**
- Difficulty gaining weight (feeding difficulties as an infant/child)
- Delayed walking (first walked at 15 months of age or later)
- Delayed talking (speech difficulties)
- Short stature (woman < 5 feet tall; man < 5 feet, 4 inches)
- Seizures

**Bone**
- Abnormally shaped chest (rib cage abnormalities)
- Abnormally shaped head (skull)
- Bowing of legs (rickets in legs)
- Bowing of arms (rickets in arms)
- Knock knees (knees touch but ankles do not touch when standing upright)
- Vertebral fracture (broken bone in back)
- Non-vertebral fracture (broken bone anywhere other than back)
- Club foot deformity
- Bone pain (arms, ribs, back, legs, feet) severe enough to force you to limit your activities
- Bone pain (arms, ribs, back, legs, feet) severe enough to require pain medication
- Fractures that won’t heal
- Pseudofractures (incomplete fractures or fissures)
- Unusual gait or way of walking/running

**Joint**
Extremely flexible joints (hypermobility)
Joint swelling
Joint pain (neck, shoulder, elbow, wrist, hips, knees, ankles)

If you do experience joint pain:
Is it severe enough to force you to limit your activities?  Yes  No
Is it severe enough to require pain medication?  Yes  No

Pulmonary
Difficulty breathing
Pneumonia

Dental/Oral
Premature tooth loss (lost first baby tooth before 5 years of age)
Tooth abscess
Excessive cavities
Loss of adult teeth
Difficulty eating/swallowing

Muscle
Muscle weakness
Muscle pain

Renal
Kidney stones
Nephrocalcinosis (calcium deposits in the kidneys)

Other
High calcium levels in blood
High phosphate levels in blood
Gout

Have you ever fractured a bone?  YES  NO
If yes, please answer the following questions.

When did your first fracture occur?
Childhood
Adolescence
Adult Age

Approximately how many fractures have you had?  

Please indicate the location of the fracture and the approximate date of each fracture:

<table>
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<tr>
<th>Location of Fracture (Foot, Arm, Leg, Back, Ribs, etc.)</th>
<th>Year</th>
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How many of your fractures were caused by…? (insert number of fractures)
Trauma (impact, force, accident)
Other Reasons (fatigue/exhaustion fractures, no obvious reason)
How many of your fractures were...? (insert number of fractures)

_____ Complete (impact, force, accident)
_____ Incomplete (pseudofractures)

If you have had incomplete or pseudofractures...

How long did it take for the pseudofractures to be diagnosed?

_____ Immediately
_____ 2 to 4 weeks
_____ 1 to 2 months
_____ 2 to 3 months
_____ Longer than 3 months

Approximately how long did it take for the pseudofractures to heal?

_____ 1 to 2 months
_____ 2 to 3 months
_____ 3 to 6 months
_____ 6 to 12 months
_____ More than 1 year

Have you ever had any of the following medical procedures?

_____ EMG (test that measures electrical activity in muscles)
_____ EEG (test that measures electrical activity in your brain using electrodes)
_____ Nerve conduction study (test that measures electrical activity in nerves)
_____ Muscle biopsy
_____ Kidney ultrasound
_____ Barium swallow study (x-ray of digestive tract after drinking liquid that shows up on x-ray)
_____ Bone biopsy

Have you ever had any of the following surgeries?

_____ Skull surgery
_____ Stapling of growth plates (8-plates)
_____ Fracture fixation with plates and screws
_____ Fracture fixation with steel or titanium rods within the bone
_____ Fixateur externe
_____ Joint replacement (specify joint)
_____ Rib replacement
_____ Osteotomy (surgical correction of a bone deformity that required cutting into bone)
_____ Club foot corrective surgery
_____ Dental implant surgery (to replace missing teeth)
_____ Root canal surgery

If you have had surgery for any complication of hypophosphatasia, please indicate the reason for the surgery and the approximate date of the surgery:

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<th>Reason for Surgery</th>
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Are you currently receiving any of the following out-patient health services?

_____ Physical Therapy
_____ Respiratory Therapy
_____ Home Health Care
_____ Massage Therapy
_____ Acupuncture

_____ Occupational Therapy
_____ Dietary Therapy/Nutritional Consultation

MEDICATIONS

Please list any PAIN medications you are currently taking including name, dosage and frequency.
Please list any OTHER medications you are currently taking including name, dosage and frequency.

_____________________________________________________________________________________

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MOBILITY

Has your home been modified due to your disease? _____ YES _____ NO

If yes, check all areas of your home that have been modified:

_____ Kitchen       _____ Thresholds/Entryways

_____ Bedroom       _____ Bathroom

Please indicate if you are using paid assistance for the following activities due to hypophosphatasia:

_____ Household activities (cleaning, shopping, cooking, etc.)

_____ Family care (watching over children, making appointments, etc.)

_____ Nursing care (medications, equipment, etc.)

_____ Bodily care (bathing, grooming, etc.)

Please indicate which of the following aids you are using or have ever used. Check all that apply:

_____ mechanical lift (car)

_____ adjustable chair (not a wheelchair)

_____ handicap ramps

_____ adjustable bed

_____ handrails

_____ orthotics (braces)

_____ cane

_____ stander

_____ crutches

_____ motorized scooter

_____ walker

_____ toilet lift

_____ manual wheelchair

_____ power wheelchair

_____ shower chair

_____ none of the above

Are you currently using a wheelchair? _____ YES _____ NO

When did you start using the wheelchair? _____ / _____ Month Year

Are you currently using a walking device (cane, walker, etc.)? _____ YES _____ NO

When did you start using a walking device? _____ / _____ Month Year

RESPIRATORY

Do you currently use a respiratory support device(s)? _____ YES _____ NO

If yes, please check all that apply:

_____ Ventilator (with trach tube)

_____ CPAP

_____ BiPAP

_____ Supplemental oxygen

_____ Other, please specify _______________________

How has your hypophosphatasia developed over the past 5 years?

_____ Improved

_____ Worsened

_____ Unaltered

List the three symptoms or complications from hypophosphatasia that interfere most with your life

1. _____________________________________________________________

2. _____________________________________________________________

3. _____________________________________________________________

Thank you for your time and effort in completing the survey! To show our appreciation, we will donate a small grant of $20 USD or 15Euro (use symbol, French and German versions) to the patient association of your choice. Please select the patient group below:

US Soft Bones

HPP ev

Hypophosphatasie Europe

CORD
If you wish to be acknowledged for sending the donation, please provide your first and last name here:________________ (this name will be sent only to selected patient group above, and not to the survey sponsor).