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

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Thank you for completing this survey!

For each of the following questions, please mark an ✖️ in the one box that best describes your answer.

1. In general, would you say your health is:

   ▼ Excellent ▼ Very good ▼ Good ▼ Fair ▼ Poor
   ☐1 ☐2 ☐3 ☐4 ☐5

2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

   Yes, limited a lot    Yes, limited a little    No, not limited at all
   ▼ ▼ ▼

   a Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf .................................... ☐1 .... ☐2 .... ☐3

   b Climbing several flights of stairs .................................... ☐1 .... ☐2 .... ☐3

3. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

   ▼ All of the time ▼ Most of the time ▼ Some of the time ▼ A little of the time ▼ None of the time
   ▼ ▼ ▼ ▼ ▼

   a Accomplished less than you would like .......................................................... ☐1 .... ☐2 .... ☐3 .... ☐4 .... ☐5

   b Were limited in the kind of work or other activities ............................................. ☐1 .... ☐2 .... ☐3 .... ☐4 .... ☐5
4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

<table>
<thead>
<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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</thead>
<tbody>
<tr>
<td>▼</td>
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</table>

a. Accomplished less than you would like

b. Did work or other activities less carefully than usual

5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
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</table>

6. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

<table>
<thead>
<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>
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a. Have you felt calm and peaceful?

b. Did you have a lot of energy?

c. Have you felt downhearted and depressed?

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

<table>
<thead>
<tr>
<th>All of the time</th>
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<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</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
- Pseudo fractures (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>
<thead>
<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?
<table>
<thead>
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<th>Reason for Surgery</th>
<th>Date (Year)</th>
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</table>

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

<table>
<thead>
<tr>
<th>Are you currently receiving any of the following out-patient health services?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Therapy</td>
</tr>
<tr>
<td>Respiratory Therapy</td>
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<tr>
<td>Home Health Care</td>
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<tr>
<td>Massage Therapy</td>
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<tr>
<td>Acupuncture</td>
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**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.

___________________________________________________________________________________________________________________________________________________________

___________________________________________________________________________________________________________________________________________________________

___________________________________________________________________________________________________________________________________________________________

___________________________________________________________________________________________________________________________________________________________

**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:

____ Households 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:

<table>
<thead>
<tr>
<th>mechanical lift (car)</th>
<th>adjustable chair (not a wheelchair)</th>
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</thead>
<tbody>
<tr>
<td>handicap ramps</td>
<td>adjustable bed</td>
</tr>
<tr>
<td>handrails</td>
<td>orthotics (braces)</td>
</tr>
<tr>
<td>cane</td>
<td>stander</td>
</tr>
<tr>
<td>crutches</td>
<td>motorized scooter</td>
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</table>
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).