

# 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:

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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

	Yes, limited a lot	Yes, limited some	Yes, limited a little	No, not limited
	▼	▼	▼	▼
a. Doing things that take some energy such as riding a bike or skating?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
b. Bending, lifting, or stooping?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

### 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?

Yes, limited a lot	Yes, limited some	Yes, limited a little	No, not limited
▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

### 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?

Yes, limited a lot	Yes, limited some	Yes, limited a little	No, not limited
▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

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

None	Very mild	Mild	Moderate	Severe	Very severe
▼	▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

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

Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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

Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied
▼	▼	▼	▼	▼
<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>

8. During the past 4 weeks, how much of the time do you think your child acted bothered or upset?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼
<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>

9. Compared to other children your child's age, in general would you say his/her behavior is:

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>

**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?**

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**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



**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 extern
- 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:

Reason for Surgery	Date (Year)

**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.

**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:

<input type="checkbox"/> mechanical lift (car)	<input type="checkbox"/> adjustable chair (not a wheelchair)
<input type="checkbox"/> handicap ramps	<input type="checkbox"/> adjustable bed
<input type="checkbox"/> handrails	<input type="checkbox"/> orthotics (braces)
<input type="checkbox"/> cane	<input type="checkbox"/> stander
<input type="checkbox"/> crutches	<input type="checkbox"/> motorized scooter
<input type="checkbox"/> walker	<input type="checkbox"/> toilet lift
<input type="checkbox"/> manual wheelchair	<input type="checkbox"/> power wheelchair
<input type="checkbox"/> shower chair	<input type="checkbox"/> 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).