

READY. SET. STRENSIQ.

Your Guide to Living With HPP



INDICATION

What is STRENSIQ?

STRENSIQ is a prescription medicine used to treat people with perinatal, infantile, and juvenile onset hypophosphatasia (HPP).

IMPORTANT SAFETY INFORMATION

What is the most important information I should know about STRENSIQ? STRENSIQ may cause serious side effects, including severe allergic (hypersensitivity) reactions.

Allergic reactions are common with STRENSIQ treatment and can be severe and life-threatening. Severe allergic reactions have happened in some people within minutes after receiving STRENSIQ and more than 1 year after starting treatment with STRENSIQ. Stop using STRENSIQ and go to the nearest hospital emergency room right away if you or your loved one get any of the following signs and symptoms of a serious allergic reaction:

- difficulty breathing
- choking sensation
- swelling of your eyes, lips, or tongue
- dizziness
- nausea or vomiting

- fever
- headache
- sweating
 - feeling irritable
 - chills
 - skin redness

- skin rash or hives
- itching or numbness of the tongue, lips, cheeks, or gums

STRENSIQ® (asfotase alfa) INDICATION & SELECT IMPORTANT SAFETY INFORMATION INCLUDING BOXED WARNING (cont'd)

What are the other possible side effects of STRENSIQ? STRENSIQ may cause other serious side effects, including:

- **skin thickening or pits at the injection site (lipodystrophy).** Lipodystrophy is common and has happened after several months in people treated with STRENSIQ.
- calcium build-up in the eyes and kidneys. People with HPP are at increased risk for
 developing calcium build-up in the body. Calcium build-up in the eyes and kidneys has
 happened and is a common side effect of STRENSIQ. Calcium build-up in the eyes and
 kidneys may also happen in people with HPP who are not treated with STRENSIQ. Your
 healthcare provider should check your eyes and kidneys before and during treatment
 with STRENSIO.
- immune-related effects. You may develop antibodies during treatment that may decrease how well STRENSIQ works. Tell your healthcare provider right away if you get worsening symptoms of HPP including: difficulty breathing, difficulty walking, feeling tired, bone pain, stiff joints, or loss of appetite.

The most common side effects of STRENSIQ include local skin injection site reactions such as skin redness, bruising, color change, pain, itching, hardening of the skin (induration), swelling, and bumps. These are not all the possible side effects of STRENSIQ. For more information, ask your healthcare provider or pharmacist. Call your healthcare provider for medical advice about side effects.

You will begin receiving STRENSIQ under the supervision of a healthcare provider. Tell your healthcare provider about all your medical conditions, including if you:

- have had an allergic reaction to STRENSIQ.
- are pregnant or plan to become pregnant. It is not known if STRENSIQ will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if STRENSIQ passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you use STRENSIQ.

STRENSIQ® (asfotase alfa) INDICATION & SELECT IMPORTANT SAFETY INFORMATION INCLUDING BOXED WARNING (cont'd)

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

There is a registry for people who use STRENSIQ. The purpose of this registry is to collect information about HPP and about what happens when you use STRENSIQ for a long time. For more information about this registry, talk with your healthcare provider or go to www.hppregistry.com

To report SUSPECTED SIDE EFFECTS, contact Alexion Pharmaceuticals, Inc. at 1-844-259-6783 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch

Please see full <u>Prescribing Information</u> and <u>Patient Information</u> for STRENSIQ (asfotase alfa), including Boxed WARNING regarding severe allergic (hypersensitivity) reactions.

Your Guide to Hypophosphatasia (HPP) and Treatment

Starting your journey with STRENSIQ® (asfotase alfa)

Whether you or a loved one has just been diagnosed with perinatal, infantile, or juvenile onset HPP or whether you're newly diagnosed or have had your condition for years, today is a milestone in your journey. Today, you're taking an important step with STRENSIQ.

Ready to get started? Go to STRENSIQ.com to enroll in OneSource™, Alexion's Personalized Support Program. Together we've got this!

About STRENSIQ

In the past, people diagnosed with HPP had no approved treatment for this rare condition. Today, there's STRENSIQ, the only FDA-approved prescription medicine to treat people with perinatal, infantile, or juvenile onset HPP. Taken at home or wherever you go, STRENSIQ is an injectable medication that replaces the alkaline phosphatase (ALP) enzyme in the body in order to help improve bone health.



You probably have questions about HPP, STRENSIQ, self-injection, OneSource, and more. We've got answers!

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HPP is a rare, inherited metabolic disorder that impacts bone formation, but it can also affect other areas of the body such as the brain and kidneys.

Because HPP is genetic, multiple members of your family may have a genetic variant for HPP, even though HPP symptoms may appear differently in each individual. This gene can be passed down from generation to generation. If you take a closer look at your family's medical histories, you may be able to notice signs or symptoms of HPP in others.

Ready to learn more? Read the following pages to discover what causes HPP and how STRENSIQ® (asfotase alfa) may help.

What Causes HPP?

People with HPP have a variant in the *ALPL* gene, which may cause missing or not enough alkaline phosphatase (ALP) enzyme activity. This means that people with HPP have ALP levels that are lower than the healthy normal range for their age and sex. When this is the case, the body has trouble making healthy bones. Low ALP levels can make bones soft, weak, and can cause other symptoms throughout the body.

HPP can affect people of all ages. This may include before birth, known as perinatal HPP; during infanthood, or infantile HPP; children, referred to as juvenile HPP; and adult HPP. HPP may impact quality of life regardless of age at onset, with issues such as mobility limitations, bone injuries, muscle, bone, joint pain, and depression.

HPP looks different for every person. The condition can affect people of all ages and may vary in terms of severity of signs and symptoms—even in the same family. New symptoms can appear at any age. Symptoms can continue long-term, and they may worsen over time. HPP is also a chronic condition that will not go away on its own; therefore, HPP may have a profound effect on managing daily activities.



LIVING WITH HPP

After all those years, I finally received my diagnosis, and I felt vindicated and surprisingly happy. I knew there was a treatment, and I was excited to try it."

Sheila, HPP STAR

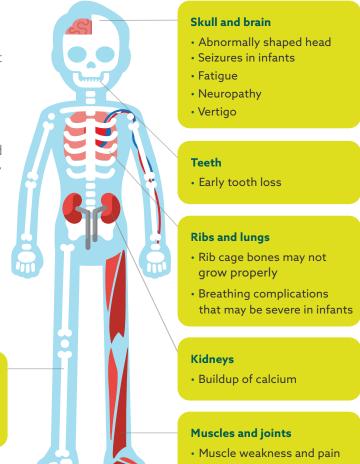
How Can HPP Affect the Body?*

HPP can affect babies. children, or adults of any age or sex. Symptoms may look different, depending on what age they began. Although it is a bone disease, HPP may impact various areas of the body. In addition, the way HPP makes you or your loved one feel may vary, and it may affect individuals differently as they age. Understanding the symptoms can give you confidence to help you or your loved one overcome the physical, social, and emotional challenges that may accompany a rare condition like HPP.

Rones

- · Weak or brittle bones
- Frequent bone injuries
- Bowing of the legs

*Not an exhaustive list.



Replace What's Missing

An enzyme called alkaline phosphatase (ALP) plays a key role in forming bones. Normally, the ALP enzyme frees phosphate so it can combine with calcium and build healthy bones. People with HPP are missing this enzyme or don't have enough of it.

Missing ALP can lead to several problems. Calcium, phosphorus-containing substances, and other raw materials may build up in areas of the body. Another consequence of low ALP is that bones can't mineralize the right way. As a result, people with HPP can have soft, weak, and deformed bones.

When your body lacks ALP, you develop weak or "soft" bones, which may lead to skeletal deformities, tooth loss, or other related symptoms. In some people, HPP may make simple tasks—such as climbing stairs, rising from a seated position, or walking—difficult.

STRENSIQ® (asfotase alfa) Replaces ALP



People born with HPP don't have enough active ALP enzyme, which is needed to "mineralize" bones.



STRENSIQ replaces the ALP your body needs to build healthy bones.



STRENSIQ frees
phosphate so it can
combine with calcium
to form the building
blocks needed to
make bones.



Calcium and phosphate work together to build healthier, stronger bones.



to learn more about how STRENSIQ replaces ALP.

STRENSIQ is a prescription medicine used to treat people with perinatal, infantile, and juvenile onset hypophosphatasia (HPP).

Studied in All Ages

Bone health and mobility¹ were studied in children and adults receiving treatment with STRENSIQ.

STRENSIQ has been studied in children and adults with signs and symptoms of HPP that appeared before 18 years of age for more than a decade.

	STUDY 1	STUDY 2	STUDY 3	STUDY 4
Initial Ages	Up to 3 years	Up to 5 years	6 to 12 years	13 to 65 years
When Did HPP Symptoms Start?	Before 6 months of age	Before 6 months of age	Before 18 years of age	Before 18 years of age (for 18 of the 19 study patients)
Number of Patients in Study	11	69	13	19
Primary Endpoints	Improvements in HPP ² -related bone health/ mineralization	Improvements in HPP-related bone health/ mineralization	Improvements in HPP-related bone health/ mineralization	Changes in PPi and PLP³ blood levels
Select Additional Endpoints	Growth ⁴ and survival	Growth and survival	Growth and mobility	Mobility and bone health/ mineralization

¹**Mobility** is a person's ability to walk.

²**HPP** is when your body lacks sufficient ALP⁵ enzyme, and you develop weak or "soft" bones, which may lead to skeletal deformities, tooth loss or pain, or other related symptoms.

³PPi and PLP are substances found in blood that are related to ALP activity and good bone and neurological health.

⁴Growth refers to changes in body size based on age over time.

5ALP is an enzyme, which is needed to "mineralize" bones. ALP frees phosphate so it can combine with calcium and form the building blocks needed to make bones.

Select Secondary Endpoints presented in this brochure are in bold in the table above. The primary endpoint is the outcome that establishes a medication's effectiveness and safety when it goes through testing. The secondary endpoints demonstrate additional effects after success on the primary endpoint is shown.

STUDY1&2

Improved Skeletal Healing

Study 1 and 2 primary endpoints

Improvements in HPP-related bone health/mineralization

Study 1

Included patients up to three years of age with signs and symptoms that appeared before six months of age. At six months, 90% (9/10) of patients responded to treatment, which was sustained at seven years (7/7).

Study 2

Included patients up to five years of age with signs and symptoms that appeared before six months of age. At six months, 63% (40/64) of patients responded to treatment, which was sustained at six years (2/2).*

*In this study, only 2 patients received STRENSIQ® (asfotase alfa) for 6 years.

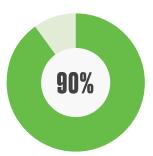


LIFE WITH STRENSIQ

HPP has always been part of my life, but it's not stopped me. I mean, there are some limitations, but I can do so much. I'm a kid first and a kid with HPP last, and I think that's what is important."

Quinn, Living with HPP

Study 1:



AFTER 6 MONTHS OF STRENSIQ

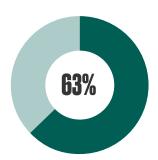
treatment achieved complete or substantial bone healing (9/10)



AFTER 7 YEARS OF STRENSIQ

treatment achieved complete or substantial bone healing (7/7)

Study 2:



AFTER 6 MONTHS OF STRENSIQ

treatment achieved complete or substantial bone healing (40/64)



AFTER 6 YEARS OF STRENSIQ

treatment achieved complete or substantial bone healing (2/2)

Skeletal Healing

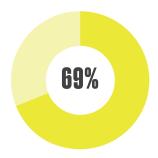


STRENSIQ® (asfotase alfa) improves bone health

Study 3 included patients from ages six years to 12 years with signs and symptoms that appeared before 18 years of age (12/12).

At six months, 69% (9/13) of patients responded to treatment, which was sustained at seven years (12/12).

· One child did not complete this study.



AFTER 6 MONTHS OF STRENSIQ

treatment achieved complete or substantial bone healing (9/13)



AFTER 7 YEARS OF STRENSIQ

treatment achieved complete or substantial bone healing (12/12)

STUDY 3

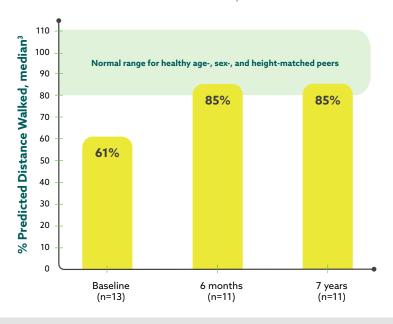
Improvements in Mobility¹: 6-Minute Walk Test

Study 3 Select Secondary Endpoint



Mobility

Six-Minute Walk Test (6MWT)² was conducted in 11 out of 13 children aged 6-12 with HPP during the study. In the 11 children, the % of their predicted³ walking distance reached the normal range after six months of treatment and improvements were sustained over seven years.



¹Mobility is a person's ability to walk.

²6MWT is the distance walked measured over a 6-minute time period.

³This refers to the percentage of the distance a healthy person of similar age, sex, and height would be expected to walk in 6 minutes.

STUDY 4

Change in Blood Levels Related to Bone Health

Study 4 Design

Study 4 spanned five years and included adolescents and adults from ages 13 to 65 years with signs and symptoms of HPP that appeared before 18 years of age (for 18 of the 19 study patients).

The study's two co-primary endpoints were to measure the change in blood levels at 6 months of known substances related to ALP activity and bone health: PPi¹ and PLP².

If PPi and PLP are high, ALP activity is generally low.

Study 4 Results

- The change in PLP was statistically significant³ at six months. The change in PPi was not statistically significant at 6 months. With one of the co-primary endpoints not being statistically significant, one of the objectives was not met.
- The most frequently reported side effects were injection-site reactions.
- These data are not included in the FDA-approved Prescribing Information.
- Over the initial duration of the study, STRENSIQ® (asfotase alfa) was administered at lower doses than the FDA-approved dose (weight-based dose of 6 mg/kg per week).



PPi: change was not statistically significant



PLP: change was statistically significant

1PPi stands for **inorganic pyrophosphate**, which is a substance important in the process of bone mineralization and making bones stronger.

²PLP stands for pyridoxal 5'-phosphate, also known as vitamin B6.

3Statistically Significant means that you can feel confident that the result is real and not due to chance or luck.

STUDY 4

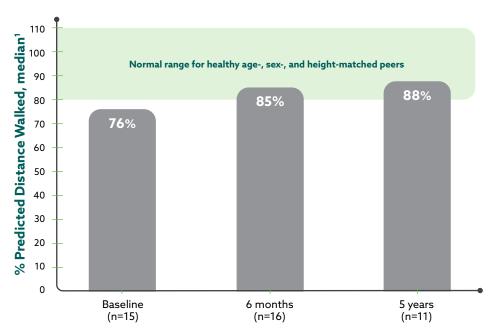
Mobility: 6-Minute Walk Test

Study 4 Select Secondary Endpoint



Mobility

Change in the 6-Minute Walk Test (6MWT) was observed by 6 months and again at 5 years.



¹This refers to the percentage of the distance a healthy person of similar age, sex, and height would be expected to walk in 6 minutes.

SUMMARY

Studies 1-4 Select Efficacy Results

STRENSIQ® (asfotase alfa) Clinical Trials

After 6 months of STRENSIQ,

- Most children had complete or substantial bone healing (Study 1, 90%; Study 2, 63%; Study 3, 69%). Improvements were sustained for up to 7 years in patients tested.
- **85% of children showed improved mobility** in Study 3, as shown by reaching the normal range for predicted walking distance (6MWT1). Improvements were sustained over 7 years in patients tested.
- Change in blood levels (PLP² and PPi³) related to ALP activity were observed in adults in Study 4.
- Change in mobility observed via the 6MWT was observed by 6 months and again at 5 vears in Study 4.

¹6MWT stands for 6-Minute Walk Test.

²PLP stands for pyridoxal 5'-phosphate, also known as vitamin B6.

³PPi stands for inorganic pyrophosphate.



KEEPING TRACK

The main thing that the medical professionals told me to do is to log everything, like any site reactions after injection."

Larry, HPP STAR

Side Effects

Adverse reactions reported in at least 10% of patients with perinatal, infantile, and juvenile onset HPP enrolled in STRENSIQ clinical trials.

Adverse reaction ¹ category or term	Perinat	Juvenile-onset HPP		
	STRENSIQ less than or equal to 6 mg/kg per week (N=66) n (%)	STRENSIQ more than 6 mg/kg per week (N=13) n (%)	Total (N=79) n (%)	STRENSIQ (N=20) n (%)
Injection-site reactions	38 (58)	6 (46)	44 (56)	18 (90)
Ectopic calcifications	3 (5)	0 (0)	3 (4)	11 (55)
Lipodystrophy	12 (18)	2 (15)	14 (18)	14 (70)
Hypersensitivity reactions	7 (11)	3 (23)	10 (13)	2 (10)

Adverse reactions are from the combined period of 6 mg/kg and above (ie, total drug exposure regardless of starting dose and intermediary doses as long as the patient reached doses >6 mg/kg).

Studies Continue in Adults

Collecting real-world experience of adults with HPP taking STRENSIQ® (asfotase alfa)

Clinical trials, conducted in a very controlled setting, are crucial for gaining knowledge on whether a medication is safe and effective for patients to use. Once approved, use of a medication by patients can be studied in a real-world setting. This information is known as real-world data.



Traditional clinical trials use:

- Strict criteria for patients to be included or excluded from the study.
- Detailed protocols that need to be followed.



Real-world evidence studies use:

- Observations of patients during routine healthcare.
- A variety of sources such as de-identified electronic medical records, claims data, or registries.

What does this mean?

Researchers continue to study STRENSIQ in adult patients with pediatric-onset HPP using real-world evidence studies. Such studies include analyzing data collected through the HPP Registry. We are dedicated to understanding the effects of STRENSIQ in adults with HPP in their everyday life.





GET

Once your doctor prescribes STRENSIQ® (asfotase alfa) to treat your or your loved one's HPP, it's time to get set to begin your treatment.

Enroll in Alexion's OneSource™ personalized patient support program and you'll receive your Patient Starter Kit, and with your first shipment, you'll receive the STRENSIQ Injection Kit. You'll also be paired with a OneSource Case Manager who can answer your questions, provide injection support, help with insurance and financial assistance, and more.

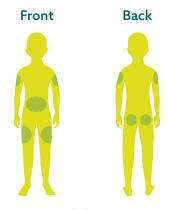
Continue reading to learn more about how to get started on STRENSIQ.

Taking STRENSIQ® (asfotase alfa)

STRENSIQ is given as an injection under the skin (called a subcutaneous injection) and can be conveniently taken at home or wherever you go. Your doctor will prescribe a specific dose of STRENSIQ based on your weight and will decide how often it should be given.

STRENSIQ is dosed in a variety of different strengths, which is indicated by the color of the vial and the box. It's important to follow your doctor's dosing instructions exactly. Your doctor will determine the dosage that's right for you. As your weight changes, your dosage may also change depending on your doctor's recommendations.

It is important to use STRENSIQ as described in the Patient Prescribing Information and Instructions for Use, or as instructed by your doctor, nurse, or pharmacist.



Recommended injection sites
STRENSIQ can be injected under the skin
of the stomach area, upper arms, upper
legs, or buttocks.

Speak with your nurse, doctor, and/or pharmacist for more information on where to inject STRENSIQ.

Do not inject STRENSIQ into the buttocks for infants.



Click here to watch our "STRENSIQ Injection How-To" video and see how HPP STARs properly inject STRENSIQ.

Storage

DO



Store STRENSIQ in its original package in the refrigerator at 36°F to 46°F (2°C to 8°C) until you are ready to use it.

DO NOT



Freeze your STRENSIQ vials. Do not use STRENSIQ if it has been frozen.



Protect STRENSIQ from light until you are ready to use it.



Shake your STRENSIQ vials.



Remove STRENSIQ from the refrigerator 15 to 30 minutes before use, then be sure to use it within three hours.



Use STRENSIQ after the expiration date printed on the package.

STRENSIQ comes in single-use vials. After injection, always properly discard vial with any leftover STRENSIQ.

Traveling with STRENSIQ? See <u>page 36</u> for more information.

The Support You Need for a Strong Start

Get ready to meet the new members of your HPP team: OneSource $^{\text{TM}}$, a free patient support program offered by Alexion, and PANTHERx Rare specialty pharmacy.

After signing up with OneSource, you will be paired with a dedicated Case Manager who can answer your questions about HPP and STRENSIQ® (asfotase alfa). Your Case Manager will send you the STRENSIQ Patient Starter Kit (see page 29 for details) and is here to help you throughout your treatment journey.

While OneSource will be your first point of contact as you make STRENSIQ part of your routine, PANTHERx Rare handles the prescription logistics and will contact you throughout treatment.

Here's how it works...



Prescription submitted by doctor; **OneSource** enrollment submitted by doctor or patient



OneSource

Patient opts to enroll into OneSource patient support services and receives a welcome call

PANTHERx Rare

Manages patient's prescription with their doctor





Contacts patient to discuss dosing, STRENSIQ shipment logistics, and needle disposal arrangements



PANTHERx Rare

Sends Injection Starter Kit, including first shipment of STRENSIQ, to patient and prepares ongoing refills

OneSource

Stays in touch with patient to help with questions or concerns about STRENSIQ or HPP



OneSource

Patient receives the STRENSIQ Patient Starter Kit from OneSource



Works together with patient's insurance to verify benefits and assist with appeals*

*If patient faces challenges throughout the appeal process, OneSource can help.



As patient continues treatment with STRENSIQ, OneSource and PANTHERX Rare can provide educational resources and tools along the diagnosis and treatment journey

Setting You Up for Success

Once you receive your first shipment of STRENSIQ, you will also receive the Injection Starter Kit. Inside, you'll find guidance on how to administer injections and tools for how to develop a routine that works for you.

Life With Treatment

Establishing a routine that's convenient for you makes it easier to remember to take your injections and helps build your confidence with every experience. As STRENSIQ® (asfotase alfa) becomes a natural part of your daily life, your OneSource™ Case Manager will follow up with you on your progress and continue to provide the support you need to be successful.

Here are a few ways OneSource supports you as you continue your journey with STRENSIQ:



Ongoing Education: Answers questions that you or your healthcare provider may have about HPP, your condition, or STRENSIQ.



Injection Support: Continues to support you with injection tips and resources throughout your treatment.



Logistical Assistance: Helps keep you on track and avoid interruptions in treatment during insurance changes, travel plans, or other life events.



Community Connection: Shares information about rare diseases and encourages you to get involved with the rare disease community through events and meetings.



Financial Assistance: Connects you with resources to help cover the cost of STRENSIQ when needed.

Insurance Tips

Before your insurance provider approves STRENSIQ, a prior authorization may be required. Your insurer may require information from your doctor such as medical history, *ALPL* genetic testing, and other results from lab tests or exams that confirm your diagnosis.

After your initial insurance approval to receive STRENSIQ, your insurance provider may require more information for continued approval in the future at specified times (for example, every 12 months). Likewise, if you change insurance for any reason, a new authorization may be required.

Sound complicated? Don't worry! Your OneSource Case Manager can walk you through the process and help you or your loved one navigate your journey to start—and stay—on STRENSIQ.

AT ONESOURCE, WE ARE BY YOUR SIDE THROUGHOUT YOUR JOURNEY, FROM LEARNING ABOUT YOUR CONDITION TO HELPING YOU ACCESS THE THERAPY YOU'VE BEEN PRESCRIBED. PATIENTS' NEEDS ARE OUR TOP PRIORITY.

-DEANA, ONESOURCE CASE MANAGER





Click here to complete the OneSource
Enrollment and Authorization Form and check
all the boxes to receive additional materials
and follow-up communication.

Starter Kits

Once a doctor prescribes STRENSIQ® (asfotase alfa), you or your caregiver can request a STRENSIQ Starter Kit that contains information that can help you successfully begin and stay on treatment. Plus, you'll be given access to a wealth of Alexion resources and support.

Here's what's inside the STRENSIQ Starter Kit:

- OneSource™ Brochure
- 2 STRENSIQ Guide
- 3 STRENSIQ Patient Journal and Symptom Tracker
- 4 Medical Alert Card
- **5** Patient Education Event Card
- **6** Welcome Letter
- **1** US Prescribing Information
- Facebook Card





Click here for more detailed information and to order your STRENSIQ Starter Kit.

The Injection Starter Kit has supplies and information you need to start STRENSIQ treatment with success.

The Injection Starter Kit includes:

- 1 Injection Supplies
- 2 Injection IQ
- 3 Injection Supplies Mat
- Injection Site Tracker and Calendar
- STRENSIQ Travel
 Requirements Letter
- 6 OneSource Connection Card
- Welcome Letter



Ready to take the next step? Let's go!

Visit AlexionOneSource.com/Enrollment-Form to complete the OneSource Enrollment and Authorization Form. Be sure to check all the boxes on the form to receive additional materials and follow-up communication.



Learning about your condition and starting STRENSIQ® (asfotase alfa) are the first steps to taking back your life with HPP.

Now it's time to step into an active role on your HPP treatment journey. Collaborating with your healthcare team and joining the HPP community are two great ways to embrace your health and change the things you can. Read on to discover all these great resources and more!

Take an Active Role

One of the most important things you can do is to build an open relationship with your doctors. Here are five ways to make the most of every appointment:

- **Be prepared.** Write down questions for your doctor. (See Conversation Starters on the next page.)
- Track symptoms to share with your doctor. Document any physical or emotional responses you've experienced in the Symptom Tracker provided in your Starter Kit.
- Bring along a friend or family member to serve as a "second pair of ears."
- **Take notes**—or ask your doctor if you can record your conversation using your mobile device. (Not all healthcare facilities allow recording.)
- Share your goals for treatment as well as your personal and professional goals.
 These objectives can help you and your healthcare provider make decisions that meet your needs.
- After each visit, record your progress, recent test results, and assessments in your STRENSIQ Treatment Journal to have handy for future appointments and insurance authorizations.

Use your STRENSIQ® (asfotase alfa) Treatment Journal and Symptom Tracker in this Starter Kit to write down questions between visits and keep a record of symptoms to share with your doctor.

Start the Conversation

It's important to communicate openly and honestly about your life with HPP. Your STRENSIQ Treatment Journal and Symptom Tracker can help you prepare for doctors' visits. Use the following questions to inspire an open dialogue with your treating physician.

- 1 What improvements can be expected with STRENSIQ? How will you measure these improvements?
- What are the possible side effects of STRENSIQ?
- How long will I need to stay on STRENSIQ?
- 4) Will the dose of STRENSIQ change with my age or if I lose or gain weight?
- Does STRENSIQ affect any other medications I am taking?
- 6 Once STRENSIQ is started, how often should I visit the doctor?
- How can STRENSIQ affect my lab test results? (You'll receive a Medical Alert Card with your STRENSIQ Patient Starter Kit.)
- How might HPP impact my family members?



THE POWER OF SUPPORT

Looking back to where I was before treatment to where I am now, it's a completely different place. I have a medical team that listens, and I have a treatment that's really helping me."

Ray, HPP STAR

Find Your Community

The HPP community may be small in numbers, but it's mighty in support!



Throughout the year, Alexion sponsors **STRENSIQ Perspectives** webinars and live events for people living with HPP and their caregivers. Hear from physician speakers and HPP STARs, also impacted by HPP, sharing their stories. For more information and to register, go to strensiq.com/events and follow our social media channels on Facebook, Instagram, and YouTube to find out about upcoming events and stay connected with the HPP community around the world.

HPP Support Groups



Soft Bones (<u>softbones.org</u>) provides information and a community to educate, empower, and connect people living with HPP and their families and caregivers.



The Avalon Foundation (<u>kidscaringforkids.org</u>) provides emotional and educational support to families receiving care for HPP.



Click here to learn more about resources for support.

The HPP support groups listed above are independent, nonprofit patient service organizations. Their listing in this guide does not imply endorsement of any product or company. All logos and trademarks are the property of their respective owners.

On the Go

When traveling with STRENSIQ® (asfotase alfa), keep it refrigerated throughout your trip. STRENSIQ should be refrigerated in its original package at 36°F to 46°F (2°C to 8°C) and protected from light. Before you head out on your next trip, remember the following instructions:



Plan Ahead: Factor in travel time and possible delays and consider outside temperature changes when traveling with STRENSIQ. Carry STRENSIQ in a cooler to keep it at its optimal temperature. Make sure there will be a place to refrigerate STRENSIQ when you arrive.



Keep Cool: To maintain its ideal temperature, STRENSIQ may be stored in an insulated cooler. If traveling long distances by plane, call ahead to your airline to find out if refrigeration is provided in-flight. Always travel with STRENSIQ in your carry-on luggage. Do not store STRENSIQ in your checked luggage.

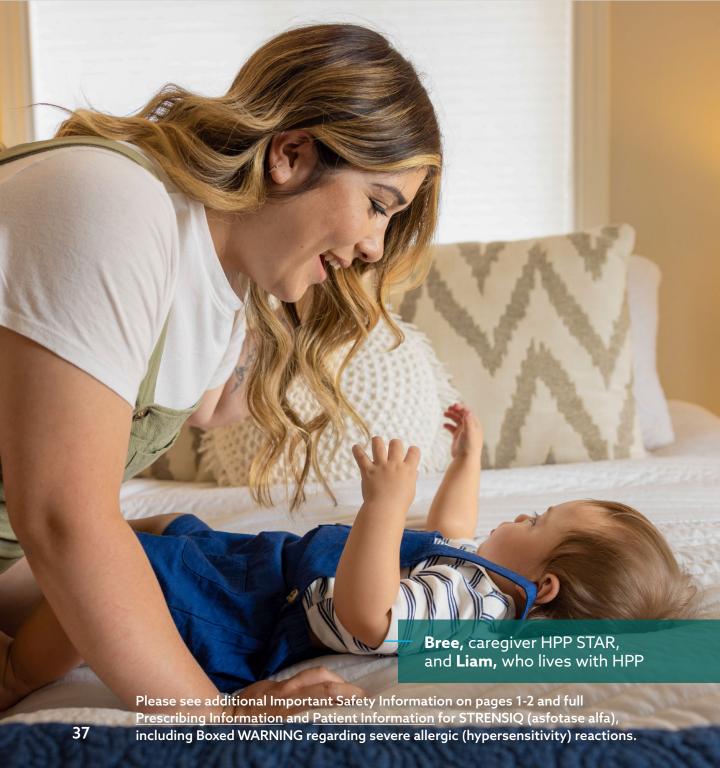


Remember, your Injection Starter Kit includes a travel letter that can be shown to airline staff to help ensure your STRENSIQ travels with you appropriately. Contact your OneSource™ Case Manager at 1.888.765.4747 for more travel tips and resources, such as travel coolers.

Click here to watch our STRENSIQ Travel
Tips video.



Please see additional Important Safety Information on pages 1-2 and full Prescribing Information and Patient Information for STRENSIQ (asfotase alfa), including Boxed WARNING regarding severe allergic (hypersensitivity) reactions.



TAKE CARE

If you're a caregiver, take a bow.

You do so much for your loved ones and take it all in stride. This section of our Guide is dedicated to you and to helping make your life easier with information and resources specifically designed for people caring for loved ones with HPP.

Your health and well-being are connected to the health and well-being of your loved ones.

Give Yourself Care

As the primary caregiver and advocate for a loved one with HPP, you're probably a pro at multitasking, but it's common to feel uncertain or simply tired. Give yourself a break. Taking care of yourself is every bit as important as taking care of your loved one. Consider these suggestions for helping yourself and your loved one on your journey together with HPP:



Create a tag team: Ask a friend or family member to learn how to give STRENSIQ® (asfotase alfa) to your loved one so you can enjoy an occasional "night off."



Take time for yourself: Even if it's just an hour a day, set aside some "me time" to relax. While taking care of your loved one might be your passion, taking time to engage in a favorite hobby or activity will allow you to recharge and unwind so you can continue advocating for the one you love.



Talk about it: Caring for a loved one with a chronic condition can take an emotional toll. Consider speaking to a trained professional to help you process your feelings and keep going strong.



Click here to register to speak to someone impacted by HPP.

Ask for Help

You don't have to navigate your loved one's HPP on your own. Asking for help can be one of the hardest parts of caring for someone with a chronic condition like HPP. Sometimes it may seem easier to handle tasks yourself rather than asking someone else to lend a hand.

Remember that people generally want to help but sometimes just don't know how. No one can read your mind! By asking for help with a specific task, you're not just gaining assistance, you're allowing others to be there for you—which helps them, too!

Tips on asking for help:

- Say "yes" when someone asks to help you
- Be specific
- Don't apologize
- Share your gratitude

Ideas for ways others can help you:

- Transportation
- House or yard work
- Grocery shopping
- Mobility assistance during travel
- · Flexible work hours

Planning and anticipating your own needs might make it easier to navigate social/work-related situations, travel, and common day-to-day activities.

Want to connect with other HPP caregivers?
Turn to page <u>35</u> for details about HPP support organizations.

Develop a Routine

One of the best things you can do for your loved one is to be confident in how and when to administer their medication. In your loved one's first shipment of STRENSIQ® (asfotase alfa), you will receive an Injection Starter Kit. (See <u>page 30</u> for a detailed description of what you'll receive.)

Tips for Injecting STRENSIQ With Confidence

- Carefully read the Patient Information and Instructions for Use before your loved one starts STRENSIQ and each time they get a refill.
- Only inject under the skin (subcutaneously) in areas with a substantial amount of fat. STRENSIQ can be injected under the skin of the stomach, buttocks (except in infants), upper arms, or upper legs. Use the Injection Starter Kit for guidance.
- Use the Injection IQ: Quick Tips to Prepare for Your Injection booklet to identify injection sites and to help you administer STRENSIQ.
- Use the Injection Site Tracker to record each injection site and rotate between them.
- Use the Injection Supplies Mat to keep your loved one's injection materials clean and organized during injections.
- **Keep up with symptoms** between doctors' visits with the STRENSIQ My Treatment Journal and Symptom Tracker.
- Always use the exact dose of STRENSIQ prescribed by your loved one's doctor. Before starting STRENSIQ, their doctor will speak with you about how often STRENSIQ should be injected.



Please see additional Important Safety Information on pages 1-2 and full Prescribing Information and Patient Information for STRENSIQ (asfotase alfa), including Boxed WARNING regarding severe allergic (hypersensitivity) reactions.

Growing Up With HPP



It may be hard to imagine your baby bird leaving the nest—and thankfully, that doesn't happen overnight. As your child grows up with HPP, it's important for them to take charge of their treatment. If you begin to prepare them when they are young, they'll be more likely to establish a routine that can last a lifetime.



Along the way, encourage your child to:

- Take charge of logging information into their STRENSIQ My Treatment Journal and Symptom Tracker.
- Use the Injection Site Tracker to record each injection site and rotate between them.
- Help you order supplies.
 - Contact their OneSource™ Case Manager with you when they have questions.





There are also resources for younger children and teens offered through HPP support organizations. Click here for a list of organizations and other resources.

Speak Up

As a caregiver for someone living with HPP, advocating for your loved one becomes a part of daily life. Whether at the doctor's office, at school, or with babysitters, neighbors, and friends, being able to communicate effectively about your loved one's condition will help you—and them—stay safe and healthy.

Tips for Confident Conversations Wherever You Go

- Use the STRENSIQ® (asfotase alfa) Treatment
 Journal and Symptom Tracker to keep up
 with HPP symptoms and challenges between
 appointments, and keep an ongoing list of
 questions for the doctor.
- Fill out the Medical Alert Card provided in the Starter Kit and put your loved one's medical information in their mobile device. Inform teachers and coaches of the location of their Medical Alert Card.
- Invite your loved one to develop their own age-appropriate way of describing HPP so they can share their diagnosis with friends and other family members.



Going to School With HPP

If teachers and administrators at your child's school don't know anything about HPP, you can become the teacher by providing a written document that outlines your child's needs. Be sure to include the following information:

- A written request from your child's healthcare provider for accommodations and assistive mobility devices, such as wheelchairs, walkers, or canes (if needed)
- Any medication or administration instructions in case the school nurse needs to provide care
- Possible situations that could arise and how to handle them
- **Instructions on whom to contact** in case of an HPP-related emergency
- Your pediatrician's and specialist's names and numbers

You may want to request a meeting with the school guidance office, the school nurse, your child's teacher, and any other specialists at school who assist with student accommodations. Then work with the school's staff to figure out a plan for your child's day-to-day activities.



Click here to save a copy of this READY. SET. STRENSIQ guide and find other information on HPP at STRENSIQ.com to share with your child's school administrators, school nurse, and teachers.

Get Ready for College

As your teen approaches their college years or stretches their wings to leave the nest, how can you best prepare them for taking responsibility for their treatment? Let them know that you and $OneSource^{TM}$ are just a phone call away.

- Suggest that your student contact their Resident Advisor (RA) before they get to campus and provide them with a copy of (or link to) this guide. Likewise, encourage them to share the basics of HPP and STRENSIQ® (asfotase alfa) with roommates.
- **Talk to campus administrators** about options for receiving refrigerated shipments and safely storing STRENSIQ.
- Talk with PANTHERx/FedEx about shipments and request a sharps container and disposal instructions for campus use from PANTHERx.
- **Encourage** your almost-adult child to stay in touch with OneSource about logistical support and upcoming appointments.



SUPPORTING LOVED ONES

We take his challenges day by day and celebrate these accomplishments both big and small like there's no tomorrow. Liam is our warrior, and he inspires us everyday."

Bree, caregiver HPP STAR

Please see additional Important Safety Information on pages 1-2 and full <u>Prescribing Information</u> and <u>Patient Information</u> for STRENSIQ (asfotase alfa), including Boxed WARNING regarding severe allergic (hypersensitivity) reactions.



Lean on OneSource™

When you enroll in the OneSource program, you'll work with a dedicated team of OneSource Case Managers with expertise in rare conditions and health insurance.

With complimentary, personalized patient support services, OneSource helps you begin STRENSIQ treatment and continue without disruptions—giving you more confidence to live your life.

Call **1.888.765.4747** or visit <u>AlexionOneSource.com</u> to hear from a OneSource Case Manager.

