

# The Caregiver's Guide TO THE Primary HLH Hospital Experience



An overview of the people and places you'll see during your hospital stay.

HLH=hemophagocytic lymphohistiocytosis.

## What Is GAMIFANT?

GAMIFANT is a prescription medicine used for the treatment of adults and children (newborn and older) with primary hemophagocytic lymphohistiocytosis (HLH) whose disease has come back or progressed, or other medicines have not worked well enough or cannot be tolerated.

## IMPORTANT SAFETY INFORMATION

**GAMIFANT can cause serious side effects, including infections.** GAMIFANT is a medicine that affects your immune system and may lower the ability of your immune system to fight infections. GAMIFANT may increase your risk of serious infections that can lead to death. These infections include tuberculosis (TB), histoplasmosis, herpes zoster infection (shingles), and other infections caused by viruses, fungi, or bacteria that can spread throughout the body. Your healthcare provider will:

- Test you for TB before you start treatment with GAMIFANT
- Treat you with a medicine for TB if you are at risk for TB or if you have a known positive TB test. Infections are common in people treated with GAMIFANT

**Please see Important Safety Information on pages 2-3. [Click here](#) for Patient Medication Guide for Gamifant.**



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### **Before starting GAMIFANT, tell your healthcare provider all of your medical conditions and if you:**

- Had TB in the past, or if you or a member of your family have been in recent close contact with someone with TB
- Have had a positive TB skin test (purified protein derivative test)
- Currently have an infection or have a history of infections, including histoplasmosis or herpes zoster (shingles)
- Are being treated for an active infection
- Have symptoms of an infection such as fever; sweat and chills; cough; breathing problems; blood in mucus (phlegm); or warm, red painful skin or sores on your body
- Are pregnant or plan to become pregnant. It is not known if GAMIFANT can harm your unborn baby
- Are breastfeeding or plan to breastfeed. It is not known if GAMIFANT passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby during treatment with GAMIFANT

**Please see additional Important Safety Information on page 3.  
[Click here for Patient Medication Guide for Gamifant.](#)**



## IMPORTANT SAFETY INFORMATION (continued)

**Your healthcare provider will give you medicine to help prevent certain infections before you receive GAMIFANT.**

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

**After starting GAMIFANT,** tell your healthcare provider if:

- New symptoms of an infection appear
- Symptoms of an infection that you already had when starting GAMIFANT worsen. Your healthcare provider will monitor you closely for signs and symptoms of infections during treatment with GAMIFANT

### **GAMIFANT can cause serious infusion reactions.**

These are common, can also be severe, and can happen during or shortly after treatment with GAMIFANT. Your healthcare provider may temporarily stop your infusion and treat your symptoms before continuing your infusion if you have severe infusion reactions. Tell your healthcare provider right away if you get any of the following symptoms:

- Skin redness
- Itching
- Fever
- Rash
- Excessive sweating
- Chills
- Chest pain
- Shortness of breath
- Nausea or vomiting
- Lightheadedness or dizziness

**The most common side effects of GAMIFANT include** high blood pressure (hypertension) and fever.

**These are not all the possible side effects for GAMIFANT. For more information, ask your healthcare provider. You can also see the full Prescribing Information for GAMIFANT at <https://gamifant.com/pdf/Full-Prescribing-Information.pdf>.**

**To report suspected adverse reactions, contact Sobi North America at 1-866-773-5274 or FDA at 1-800-FDA-1088.**

**Please see additional Important Safety Information on page 2. [Click here](#) for Patient Medication Guide for Gamifant.**

## Staying in the hospital

You probably first went to the hospital for help finding out why your child is sick. That's because the hospital has many different specialists, or doctors who focus on specific conditions. They ran special tests to check for primary HLH. Now that your child has been diagnosed, he or she will likely stay there for treatment.

The hospital is a big place, which can be overwhelming. Keep in mind that it has many resources and doctors who can help care for your child. This guide has information about different places and people you and your child may see. It also offers tips for making the stay more comfortable.

We hope you find it helpful as you prepare for your child's hospital stay.



**Please see Important Safety Information on pages 2-3. [Click here for Patient Medication Guide for Gamifant.](#)**

## Getting ready for treatment

Once primary HLH has been diagnosed, treatment usually begins right away. It may last for many months, and the journey can be mentally, physically, and emotionally draining for everyone in the family.

- **Induction therapy** is the first step in treatment. The goal is to get symptoms under control in preparation for a bone marrow transplant
- **Continuation therapy** is the next step. During this time, the doctor will make sure that symptoms stay under control before transplant

### What if treatment isn't working?

**There is another medicine the doctor may try. Gamifant is the first and only FDA-approved treatment for patients with primary HLH who:**

- Don't get better with other medicines
- Have symptoms that come back or get worse OR
- Can't tolerate side effects from other medicines

### Packing for the hospital stay\*

#### *For You*

- A change of clothes, pillow, and warm socks
- Your toothbrush and other toiletries
- Any medicine you will need to take
- Your cell phone and charger
- A notebook and pen
- Water bottle and snacks
- A book, tablet, laptop, or craft project to help pass the time

#### *For Your Child*

- A list of their medicines
- Books to read with them
- A framed family photo
- Familiar items from home such as blankets, stuffed animals, music, and toys

\*Please check with your doctors and nurses that the items you're bringing are okay to have in the hospital.

**Please see Important Safety Information on pages 2-3. [Click here for Patient Medication Guide for Gamifant.](#)**

## Meet your care team

Leading up to your child's diagnosis, you probably met many doctors, nurses, and other medical team members. Some of these people may also be involved in treating your child for primary HLH. Knowing a bit about each of their roles may help you feel better informed and a little less overwhelmed.

### Critical Care Specialist

These doctors treat symptoms that need attention right away. Critical care specialists usually work in the intensive care unit of a hospital. Pediatric critical care doctors and nurses have special training in treating infants and children.

### Infectious Disease Specialist

An infectious disease specialist diagnoses and treats serious infections, like those that might occur in a patient who has primary HLH.

### Gastroenterologist/Hepatologist

A gastroenterologist deals with illnesses that affect parts of the body that are involved in digestion such as the stomach, intestines, and esophagus. A hepatologist is a gastroenterologist with extra expertise in the liver, pancreas, and gallbladder.

### Rheumatologist

These doctors diagnose and treat conditions that affect muscles, bones, and joints. They also treat a group of immune system disorders called *systemic autoimmune diseases*. In these conditions, the immune system attacks the person's own body, leading to inflammation that can cause pain, swelling, and organ damage.

### Hematologist/Oncologist

A "hem/onc" is a doctor who focuses on diseases of the blood and cancer. Hem/oncs are also experts in primary HLH. It's likely that a hem/onc diagnosed your child and will be treating them moving forward.

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### **Nurses**

Nurses are experts in the daily medical care that patients need. They do things such as give patients medicine and keep track of their symptoms.

### **Genetic Counselors**

Genetic counselors specialize in knowing about genes and conditions that children can inherit from their parents, such as primary HLH.

### **Transplant Team**

This team includes doctors who perform transplants and nurses who keep track of a patient's progress. It also includes counselors, who provide information to patients and families, and health insurance experts.

### **Social Workers**

Hospital social workers help patients and families understand illnesses like primary HLH. They offer support as families deal with their emotions and counseling to help them make decisions.



Learn more by checking out the Specialist 101 series on [GamifantCares.com/pHLHResources](https://www.gamifantcares.com/pHLHResources).

Please see Important Safety Information on pages 2-3. [Click here](#) for Patient Medication Guide for Gamifant.

## Parts of the hospital

Just as you've met and talked with many medical specialists, you've probably spent time in different parts of the hospital. Here is some information about what usually happens in them.

### **Emergency Room (ER)**

This is the department where patients with urgent, sometimes life-threatening, symptoms go for care.

### **Pediatric Intensive Care Unit (PICU)**

Infants, children, and teen patients are treated in the PICU when their symptoms are serious and need to be watched closely.

### **Rheumatology/Immunology Unit**

Specialists in this department diagnose and treat disorders of the immune system—the system of organs, cells, and chemicals that work together to protect the body.

### **Infectious Disease Unit**

This unit focuses on illnesses caused by organisms, such as bacteria, viruses, fungi, or parasites. Before a patient is diagnosed with primary HLH, they may visit this unit to see if an infection is causing their symptoms. Later, the unit might be called in if the patient gets an infection during their hospital stay.



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### Hematology/Oncology Unit

The Hematology/Oncology department diagnoses and treats patients who have cancer or blood disorders like primary HLH.

### Infusion Center

Some patients have conditions that can't be treated with medicines that are taken by mouth. The Infusion Center provides medicines to these patients through a needle or catheter (a thin tube that carries fluids into the body).

### Diagnostic Imaging Unit

In this unit, special tools such as X-rays, ultrasound, CT, and MRI scans are used to take pictures of what's going on inside the body. These pictures, or images, can help doctors diagnose diseases.

CT=computed tomography; MRI=magnetic resonance imaging.

### Take care of yourself, too

**Your child is sick, and you'll do anything to make them better. But if you don't take care of yourself, you won't be as able to take care of them. Here are some tips to help you get through this tough time:**



**Take breaks**—even for just an hour or 2



**Eat right**—bring healthy snacks like fruit, granola bars, or nuts with you



**Exercise**—take a brisk walk, ride a bike, or do yoga to clear your mind and boost your energy level

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*Learn more*

Visit [GamifantCares.com](https://GamifantCares.com) or  
call Gamifant Cares Support  
Services at 1.833.597.6530

## gamifant cares<sup>™</sup>

Support for the journey ahead

### Help is here

When your family is dealing with primary HLH, it's important to know that you are not alone.

If your doctor decides that Gamifant is right for your child, **Gamifant Cares** can offer patient support programs to you and your family at no cost throughout treatment with Gamifant.

**Gamifant Cares** can assist with personalized support and resources including:

- Navigating and understanding the insurance process
- Providing financial assistance information for eligible patients, and
- Providing educational materials and nursing support through the Sobi Nurse Case Manager program

### You're in good hands at the hospital

We hope the information in this guide helps you and your child feel prepared for your hospital stay and the primary HLH journey.

#### Common side effects of GAMIFANT

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