



## An overview for teachers

Chronic granulomatous disease (CGD) is a rare disease found in 1 out of every 200,000 people born in the United States. Since CGD is a chronic condition, a person will have CGD for all of his or her life.

People with CGD have an immune system that isn't working right and makes them susceptible to frequent and sometimes life-threatening bacterial and fungal infections. A healthy immune system can fight off infections from bacteria and fungi, also called pathogens. An immune system with CGD can typically stop viral infections like a cold or the flu but can't stop serious infections caused by certain bacteria and fungi. It is important to remember that **CGD is NOT an allergy.**

### Where pathogens can be found

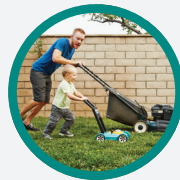
Pathogens include harmful bacteria and fungi that can cause serious, life-threatening infections in people with CGD. Bacteria and fungi can be found in places all around us and at school, including in or on:



**Wood chips** on playgrounds



**Soil and mulch** in gardens and house plants



**Clippings** from freshly mown grass



**Hay bales**



**Standing water** in lakes and ponds



**Dust** from new construction and air vents



**Dander and dirt** in carpets and on pets



**Mold** in sheds, basements, caves, and barns

People with CGD can still have fun outdoors, but they should avoid activities and environments that can present hazards. Make sure to discuss any upcoming field trips, activities, or classroom projects with the student's family to ensure they are safe for him or her to participate in.

### Additionally, be aware that certain times of the year can cause bacteria and fungi to be more plentiful

#### During spring,

rain showers can create puddles filled with bacteria.

#### During summer,

dry weather can lead to more dirt and spores in the air.

#### During fall,

it's best to avoid hayrides or being around anyone raking leaves.

To learn more about the seasonal changes that may impact a child with CGD, visit [CGDConnections.com](http://CGDConnections.com).



## Knowing and spotting the signs and symptoms

To anyone else, a low-grade fever or a scrape from a fall isn't a big deal. For a person with CGD, it can be serious or life threatening and may lead to lengthy hospitalizations. As a teacher or administrator, you should know the signs and symptoms in case medical help is needed, including when your student exhibits the following or says something's not right:



- Stomach pain
- Pain when eating or peeing
- Vomiting after eating
- Constant diarrhea
- Fever, cough, constant tiredness, or bone and/or joint pain
- Skin infections that cause boils, blisters, and sores
- Symptoms of pneumonia
- Swollen lymph nodes

### Listen to the student when he or she says something's not right

- Many people with CGD can tell when something isn't quite right. In some cases, it's an unusual pain, or **their body just feels "off"**
- A buildup of granulomas or inflammation in the intestines can necessitate **frequent trips to the bathroom**
- Always let a child with CGD go to the nurse to get **cuts or scrapes cleaned and bandaged**
- If the student **says they're feeling sick**, it's important to alert his or her parents



### Learn more at [CGDConnections.com](http://CGDConnections.com)

A great way to stay up to date with tips and suggestions that can benefit you and your student with CGD is to visit [CGDConnections.com](http://CGDConnections.com). CGD Connections™ features practical tips and helpful advice about living life to the fullest with CGD. We are on Facebook too at [Facebook.com/CGDConnections](https://www.facebook.com/CGDConnections).



# Preparing your classroom for a child with CGD

## Be prepared for long absences





Your student may have an IEP or a 504 plan in place. If so, reference that for day-to-day classroom needs, as they will be part of the plan. If a student with CGD does get an infection, it can result in a lengthy hospital stay, from 2 weeks to several months. Keeping a student current on his or her schoolwork during long absences benefits everyone. Here are some guidelines for managing their extended absences:

- Confirm that it is written in the student's IEP or 504 plan that he or she has a chronic illness that may cause extended absences
- Identify school policies and procedures that need to be addressed. Determine who will be the liaison between the family and the school. In some cases, it is the special education office; in others, it may be the nurse
- Determine whether a doctor's note is necessary for a student to obtain schoolwork
- An extended hospital stay may call for a reduced workload and shifting due dates for papers and tests
- Take advantage of technology. Skype a lesson to the student so he or she can stay connected with classmates!

**It may seem like keeping up with assignments would give the student one more thing to worry about during a hospital stay. That isn't necessarily so. Schoolwork can take a student's mind off everything else, and learning is a great way to feel good about yourself during tough times.**

## What to tell a substitute

It's important to inform a substitute about ways to accommodate your student with CGD. As you prepare your lesson plan, leave a note with the following information:

-  A brief overview of CGD (you may even print and include the "CGD and school: an overview for teachers" page with your lesson plan)
-  The names and contact information of teachers or senior administrators familiar with CGD
-  The phone number of the school nurse and parents
-  A list of special permissions, including permission to:
  - Go to the nurse's office when needed
  - Access bathrooms throughout the school day
  - Participate in alternative activities (such as study hall instead of outdoor recess) or use accommodations



# Making school and the classroom a safer place

Parents, teachers, and school staff should work together so everyone can feel confident about the health and safety of a child living with chronic granulomatous disease (CGD).

**Here are examples of what you can do to make your school a safe place:**

**Suggestions to help keep pathogens at bay:**



**Plan lawn care and groundskeeping for times when the windows are not open or after school hours**



**Keep bathrooms clean**

Bacteria and fungi love bathrooms and locker rooms. When cleaning bathrooms or locker rooms, use strong cleaners, including bleach, to kill anything around and behind the toilet and on the floor to keep any bacteria and fungi from growing.



**Rake leaves when the student with CGD is not present**



**Remove plants from classrooms**

Since potting soil can be full of fungi, the best place for a plant is outside. Replace plants with interesting lamps, pictures on the walls, and artwork scattered on side tables to make your classroom as unique as you want it to be.



**Alert the student's parents if an illness is going around the school**



**Prohibit smoking on school grounds**



**Go carpetless**

Try to avoid having carpet in the classroom of a child with CGD. If you're installing or replacing a carpet in a room like a library, make sure the student isn't in the room while it's being removed. And make sure to wait a few days for any dust and germs to settle before he or she comes back into the room.

## Important Safety Information

### What is ACTIMMUNE® (Interferon gamma-1b) used for?

ACTIMMUNE® is part of a drug regimen used to treat Chronic Granulomatous Disease, or CGD. CGD is a genetic disorder, usually diagnosed in childhood, that affects some cells of the immune system and the body's ability to fight infections effectively. CGD is often treated (though not cured) with antibiotics, antifungals, and ACTIMMUNE.

ACTIMMUNE is also used to slow the worsening of severe, malignant osteopetrosis (SMO). SMO is a genetic disorder that affects normal bone formation and is usually diagnosed in the first few months after birth.

### When should I not take ACTIMMUNE?

Don't use ACTIMMUNE if you are allergic to interferon-gamma, *E coli*-derived products, or any ingredients contained in the product.

### What warnings should I know about ACTIMMUNE?

At high doses, ACTIMMUNE can cause (flu-like) symptoms, which may worsen some pre-existing heart conditions.

ACTIMMUNE may cause decreased mental status, walking disturbances, and dizziness, particularly at very high doses. These symptoms are usually reversible within a few days upon dose reduction or discontinuation of therapy.

Bone marrow function may be suppressed with ACTIMMUNE, and decreased production of cells important to the body may occur. This effect, which can be severe, is usually reversible when the drug is discontinued or the dose is reduced.

Taking ACTIMMUNE may cause reversible changes to your liver function, particularly in patients less than 1 year old. Your doctor should monitor your liver function every 3 months, and monthly in children under 1 year.

In rare cases, ACTIMMUNE can cause severe allergic reactions and/or rash. If you experience a serious reaction to ACTIMMUNE, discontinue it immediately and contact your doctor or seek medical help.

### What should I tell my healthcare provider?

Be sure to tell your doctor about all the medications you are taking.

Tell your doctor if you:

- are pregnant or plan to become pregnant or plan to nurse
- have a cardiac condition such as irregular heartbeat, heart failure, or decreased blood flow to your heart
- have a history of seizures or other neurologic disorders
- have, or have had, reduced bone marrow function. Your doctor will monitor these cells with blood tests at the beginning of therapy and at 3-month intervals on ACTIMMUNE therapy

### What are the side effects of ACTIMMUNE?

The most common side effects with ACTIMMUNE are "flu-like" symptoms such as fever, headache, chills, muscle pain, or fatigue, which may decrease in severity as treatment continues. Bedtime administration of ACTIMMUNE may help reduce some of these symptoms. Acetaminophen may be helpful in preventing fever and headache.

### What other medications might interact with ACTIMMUNE?

Some drugs may interact with ACTIMMUNE to potentially increase the risk of damage to your heart or nervous system, such as certain chemotherapy drugs. Tell your doctor about all other medications you are taking.

Avoid taking ACTIMMUNE at the same time as a vaccination.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

*The risk information provided here is not comprehensive. To learn more, talk about ACTIMMUNE with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at <http://www.ACTIMMUNE.com> or 1-866-479-6742.*

Please see the [Full Prescribing Information](#) and [Information for the Patient/Caregiver](#) at [CGDConnections.com](http://CGDConnections.com).

