



## 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 their life.

People with CGD have an immune system that isn't working right, which 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

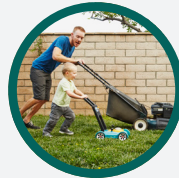
Pathogens include harmful bacteria and fungi that can cause serious, life-threatening infections in people with CGD. Bacteria and fungi can be found in places all around us and at school, including in or on:



**Wood chips** on playgrounds



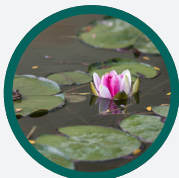
**Soil and mulch** in gardens and house plants



**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 them to participate in.

### Additionally, be aware that certain times of the year can cause bacteria and fungi to be more plentiful<sup>†</sup>

#### 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).

\*An infection is serious if you have to go to the hospital and/or get intravenous (IV) antibiotics.

<sup>†</sup>Please note that these risks can be present during multiple seasons.



## 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 chronic granulomatous disease (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:



- Fever
- Cough or chest pain that lasts longer than normal
- Pain or difficulty swallowing food
- Vomiting shortly after eating
- Weight loss or loss of appetite
- Headaches that don't go away
- Hard, painful lumps not related to an injury
- Warm, tender, or swollen areas
- Diarrhea that persists or blood in stool
- Sores with pus or rashes

### Listen to the student when they say 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 their parents



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

\*An infection is serious if you have to go to the hospital and/or get intravenous (IV) antibiotics.



# Preparing your classroom for a child with CGD

## Be prepared for long absences





Your student may have an Individualized Education Program (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 chronic granulomatous disease (CGD) does get an infection, it can result in a lengthy hospital stay, from 2 weeks to several months. Keeping a student current on their 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 they have 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 they 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 teacher

It's important to inform a substitute teacher 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 they come back into the room.

## Approved Uses and Important Safety Information

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

ACTIMMUNE is 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.

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?

Do not 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?

ACTIMMUNE can cause flu-like symptoms. At high doses, the resulting symptoms may worsen some pre-existing heart conditions.

ACTIMMUNE may cause decreased mental status, such as confusion, depression, and hallucinations. It may also cause difficulty walking and dizziness, particularly at high doses. These symptoms usually resolve a few days after reducing the amount of ACTIMMUNE you take, or if you are no longer taking it at all, as prescribed by your doctor.

Use of ACTIMMUNE may affect bone marrow function and may limit the production of cells important to your body. This can be severe and usually goes away after reducing the amount of ACTIMMUNE you take or if you stop taking it entirely as prescribed by your doctor.

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 of age.

In rare cases, ACTIMMUNE can cause severe allergic reactions and/or rash. If you experience a serious reaction to ACTIMMUNE, stop taking 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 heart 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 every 3 months while you are taking ACTIMMUNE

### 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 the longer you take ACTIMMUNE. Taking ACTIMMUNE at bedtime may help with these symptoms, and acetaminophen may help prevent fever and headache.

### What other medications might interact with ACTIMMUNE?

Some drugs, like certain chemotherapy drugs, may interact with ACTIMMUNE and could make it more likely that your heart or nervous system could be damaged. Tell your doctor about all the medicines you take.

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/safety/medwatch](http://www.fda.gov/safety/medwatch), or call 1-800-FDA-1088.

The risk information provided here is not comprehensive. To learn more, talk about ACTIMMUNE with your health care provider or pharmacist. The FDA-approved product labeling can be found at [www.ACTIMMUNE.com](http://www.ACTIMMUNE.com) or 1-866-479-6742.

**Please visit [CGDConnections.com](http://CGDConnections.com) to download a copy of the [Full Prescribing Information and Information for the Patient/Caregiver](#) and discuss with your doctor.**