



A back-to-school guide for parents

Setting up a school healthcare meeting

Parents of children living with chronic granulomatous disease (CGD) should meet with members of the school staff before classes start each year. It's important that school staff be educated about the risk of serious infections in students with CGD.

Reach out to your child's teacher(s) and have them communicate to the larger team the need for a healthcare meeting. You can also contact the school principal or another administrator who can help arrange the meeting and invite other staff members. Request a meeting that includes the following people:

- School nurse
- Principal or other senior administrator
- Teacher(s) and coach(es)
- Groundskeeping team and maintenance crew
- Guidance counselor
- Your child's healthcare provider (if necessary)
- Special education teacher or 504 plan/Individualized Education Program (IEP) coordinator

What to talk about

Here are some suggestions of topics to cover during your healthcare meeting:

- Provide an overview of CGD. A Teacher's Guide to CGD, which was designed specifically for teachers and school staff, can be found at [CGDConnections.com](https://www.cgconnections.com)
- Ask that the school nurse or other staff members alert you if an illness is going around the school. By working closely with the school staff, you can feel more confident about the health and safety of your child
- Review your child's IEP or 504 plan for the school year. You can download a guide on how to complete or revise these on [CGDConnections.com](https://www.cgconnections.com) and use it to help you through the process
- Advise the groundskeepers to inform you or your child's teacher when they will be cutting grass or mulching. It may be that the grass is cut after school when the children are not around

Activities that could put your child at risk



Being outside where there is **mulch** or **freshly cut grass**



Field trips to a **farm**



Planting seeds in **dirt**



Playing on a playground with **mulch** or **wood chips**



Being in a **moldy** or **dusty area**



Communicating with school staff about the seriousness of CGD

To anyone else, a low-grade fever or a scrape from a fall isn't a big deal. For your child living with CGD, it can be serious or life threatening and may lead to lengthy hospitalizations. Be in touch with your child's teachers and inform them of the signs and symptoms that may indicate that medical help is needed, as well as situations to be aware of. For example:

- Even minor scrapes and cuts need immediate medical attention. Ensure that staff members are aware that visits to the nurse are necessary in these instances
- Multiple bathroom breaks—even on several occasions in the same class or period—may be needed. Teachers need to allow these breaks when asked
- Your child may not want to participate in activities where they may come in contact with germs or bacteria. It is important for teachers to listen when your child has a request and/or concern about an activity and to suggest an alternative your child can do with a friend
- Remind teachers about seasonal changes. For example, autumn leaves can pose a danger to your child

Additional resources available



1. Use the **Seasonal Checklist** found on [CGDConnections.com](https://www.cgconnections.com). This was made for parents of children with CGD as a reminder of ways to make the school year more manageable while keeping CGD top of mind.
2. Remind your child's teacher that the **Teacher's Guide to CGD** can be found on [CGDConnections.com](https://www.cgconnections.com) for them to download and use throughout the year.
3. The **CGD Connections™ Facebook page** is for people living with CGD or caring for someone with CGD and offers tools, support, and more. It's a great place to check for timely tips, posts, and videos to support you and your child.

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, 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.

