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
- 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 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 woodchips
- 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. 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 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.