



A Message for Parents of Children With CDG

Be Involved in Your Child's Care

You have learned your child has a rare genetic condition called congenital disorders of glycosylation (CDG). You may feel overwhelmed and worried for your child. You may be mourning the loss of what you thought your child's life would be like.

You are likely hearing unfamiliar terms. You may have many questions, such as, "How can I help my child? What will life be like for my child and my family?"

These feelings are very natural. They are also similar to how other parents have said they have felt when they've been given this news.

Pause. Breathe in and out slowly. You can do this. Most importantly, know that many special people are going to help you. Your child's care team can answer your questions, teach you about the condition and refer you to helpful resources.

The best way to move forward is to become actively involved in your child's care. This resource includes suggestions to help you now and then throughout this journey with your child. If you have questions at any time, talk with your child's health care team.



Suggestions for Moving Forward

Learn all you can about CDG.

CDG is a complex medical topic. You may hear terms that sound like another language to you. Ask your child's health care provider about the best way to learn about CDG so you can "speak the language."

Become familiar with CDG terms so when you hear them, you know what they mean and can process the information. This resource includes a glossary that explains many terms you may be unfamiliar with. By learning everything you can, you'll be able to ask good questions and understand what health care providers explain to you.

At times, your child may be in the hospital for days, weeks or months, depending on your child's unique needs. Talk to the health care team about what to expect and what you can do to be ready.

Sometimes, when people go through difficult times, they can feel like a victim. Instead, you can feel empowered by arming yourself with knowledge.

Know your child's health history.

Keep a journal. Use it to record everything about your child, such as:

- All you learn about CDG, including terms.
- Questions you have for health care providers.
- Symptoms your child has and when he or she has them.
- Information about health care provider visits, including the provider you saw, the specialty, what happened and what was said.
- A routine record of your child's vital signs, including weight, height and developmental milestones.
- Tests your child has and the results.
- Information about when your child was hospitalized and why.
- Treatments your child has and the results of treatments. Did they work? What side effects and complications did your child have?

Consider using a three-ring binder with pockets so you can tuck in handouts into the pockets and three-hole punch documents you want included.

Bring this journal with you to all your child's health care appointments. Write information in it as soon as possible after an appointment, so you don't forget anything.

Know that you will need to be a strong advocate for your child.

You need to be the one who actively works to get your child the best care he or she can get.

Do not delay getting the care your child needs. Getting the right care early is very important for children with CDG.

This isn't always going to be easy. You are going to need to be persistent and consistent. You will have to speak up for your child who can't speak for him or herself.

Consider having someone else with you when you go to your child's health care appointments so that person can help you remember what was said and give you a "sounding board" afterward.

Find health care providers who specialize in diagnosing and treating CDG.

Having a child with a rare condition can bring unique challenges. Many health care providers have never diagnosed or treated a child with CDG. As you seek care for your child, you may encounter health care providers who don't understand the disorder or know how to provide the right care.

Find a health care organization that uses a team approach to caring for your child. By collaborating and sharing knowledge, health care providers are able to provide the best care. Find one that provides patient-centric care. This is care that places your child in the center and recognizes that you and your child are the most important members of the health care team.

Take steps to find health care providers who specialize in diagnosing and treating CDG. Make a consultation appointment with providers you consider for your child. Ask many questions including:

- Have you diagnosed and treated a child with CDG before?
- What are your specialties?
- Who will my child's health care team include at your medical facility?
- Do you communicate with my child's primary health care provider in my hometown? How do you do that communication?
- Does your facility offer a patient portal? This is an online method people can use to see medical information and communicate with providers.
- Does your team include a social worker who can help with support, financial and emotional issues?

Build a health care team you trust, a team that understands the complexity of your child's health and that listens to other providers' opinions. Find a team of providers that will fight for the answers, be thorough and compassionate.

Know the specialists your child is going to need.

Depending on your child's unique needs, he or she is going to need to be treated by many medical specialists to receive the best care. These providers may include:

- Medical genetics specialists.
- Cardiologists.
- Pulmonologists.
- Endocrinologists.
- Gastroenterologists.
- Orthopedic specialists.
- Pharmacists.
- Dietitians.
- Child life specialists.

Meet with a social worker.

A social worker can help you with all aspects of caring for a child with CDG, including:

- Supporting you, your child and your family throughout care.
- Helping you find resources for learning about the disorder.
- Referring you to community resources that address health education and support needs.
- Helping you with the financial aspects of your child's health care.
- Helping you find parent or medical networks to join and to learn from.
- Helping you with lodging and transportation when you have to travel for health care.

Share your story with others.

Think about what you are going to tell your friends and family about your child's condition. People are likely to be curious or concerned, and may have many questions or misconceptions about the condition. Honesty is usually best, but you decide what you'd like to tell your friends and family.

Sometimes it helps to be the one to talk about it first. You can answer the difficult questions and smile when others stare at you and your child.

The more you talk about your child's condition, and the more you make your vulnerability known, the easier talking about it can be.

Join a support group.

Consider joining a support group for parents of children with serious medical conditions. A social worker can help you find one that meets your needs and with whom you feel a connection. Some of these networks will be online so you can regularly connect about ongoing issues.

Allow others to help and support you.

Over time, you are going to need help. When you need help, ask for it. When people offer it, accept it. You can't do it all. Once in a while, you need a break. Allow others to support you and your child.

Ask people to help with:

- Day-to-day tasks, such as cooking meals and doing laundry.
- Providing child care to your other children, if needed.
- Providing respite care for your child. Use the time to rest, go for a walk or do something you enjoy. You are not going to be able to provide good care for your child if you don't take good care of yourself.



A Personal Message From a Parent of a Child With CDG

These profound words are shared by a parent who has a child with CDG. Her wish is that these messages can bring you comfort, hope and understanding as you move forward.

"I know it's scary right now. You've got millions of questions circling in your mind. You may be asking yourself, 'What now? Where do I begin?'"

I wish I had easy answers for you. The truth is that every parent's and every child's CDG journey is different.

You have been given a chance to gain a different perspective on what is important. You have been given the chance to celebrate every small victory that most parents take for granted. You have been given the chance to learn more about your child than most parents will ever know. You have been given the chance to care differently for your child from what most parents will ever be able to do.

As time passes, your 'new normal' will no longer feel new. You will gain answers to the unknowns every day. You are sprinting through a marathon right now. Regardless of what CDG sub-type your child has, you may be surprised at the obstacles you both can overcome. The time will come that you will be able to slow down and catch your breath.

Love for your child will carry you through even on the hardest days. Your life may no longer be the same, but the feelings of gratitude for this special child will far outweigh the feelings of stress on tough days ahead. The tears of confusion and sadness will eventually change to tears of joy.

Know that you are not alone, no matter how isolated you feel at this moment. Your child's health care team can answer your questions and help you face the challenges. Over time, they have become our CDG heroes."



This material is for your education and information only. This content does not replace medical advice, diagnosis or treatment. New medical research may change this information. If you have questions about a medical condition, always talk with your health care provider.