



PATIENT EDUCATION

*Congenital Disorders of Glycosylation
(CDG)*

MAYO CLINIC CHILDREN'S CENTER

BARBARA WOODWARD LIPS
PATIENT EDUCATION CENTER

Mayo Clinic Children's Center

For more than 100 years, teams of physicians have cared for children at Mayo Clinic.

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MAYO EUGENIO LITTA CHILDREN'S HOSPITAL

Pediatric Sub-Specialties in the following areas:

Allergy and Immunology	General Pediatric and	Plastic and Reconstructive Surgery
Anesthesiology	Adolescent Medicine	Psychiatry and Psychology
Cardiology	Gynecology, Adolescent	Pulmonology
Cardiovascular Surgery	Hematology and Oncology	Radiation Oncology
Child and Family	Infectious Diseases	Radiology
Advocacy Program	Medical Genetics	Regional (Health System)
Community Pediatrics and	Neonatal Medicine	Pediatrics
Adolescent Medicine	Nephrology	Research
Critical Care	Neurology	Rheumatology
Dermatology	Neurosurgery	Sleep Medicine Center
Developmental and	Ophthalmology	Speech Pathology
Behavioral Pediatrics	Oral and Maxillofacial Surgery	Surgery
Emergency Medicine	Orthopedic Surgery	Urology
Endocrinology and Metabolism	Otorhinolaryngology (ENT)	
Gastroenterology and Hepatology	Physical Medicine and Rehabilitation	

Pediatric Specialty Clinics:

Adrenoleukodystrophy Clinic	Dana Child Developmental and	Metabolic Bone Clinic
Aerodigestive Clinic	Learning Disorders Program	Mood Disorders Clinic
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Learn All You Can About Congenital Disorders of Glycosylation (CDG)

Finding out your child has a rare genetic disorder like CDG can be hard. Learning more about CDG can help you care for your child and make plans for the future.

Read this resource to learn about the disorder, medical terms you are likely to hear, causes, symptoms, and how the disorder may be diagnosed and treated. Also learn about the health care providers who may be a part of your child's care over time. Talk to your child's health care team at any time if you have questions.



This resource includes some wise words from a parent of a child with CDG.

Understanding CDG

Congenital disorders of glycosylation (CDG) is a large group of rare, inherited disorders that affect a complex process in the body called glycosylation. Most children who have CDG have neurological issues and symptoms, developmental problems, growth delays and problems with organs not working like they should.

Congenital means that CDG is a condition that happens at or before birth.

Notice that “disorders” is plural. This is because CDG is not just one disorder, but rather, a group of disorders. There are many types. Which type your child has depends on which body system is affected.

About glycosylation

Glycans are sometimes called “sugar trees,” “antennas” or “sugar chains” by health care providers. They are built from sugar “building blocks.”

When some people hear sugar, they think of blood sugar, blood glucose or diabetes. This is not the case with glycans, which are not used for burning calories.

Glycosylation is the process of creating, changing and attaching these sugar building blocks to proteins and lipids.

- When the sugar building blocks attach to proteins, they are called “*glycoproteins*.”
- When the sugar building blocks attach to lipids, they are called “*glycolipids*.”

When someone has CDG, his or her body cannot properly add or attach the sugar building blocks to proteins or lipids. Every single system in the body needs the process of glycosylation to work right so the body can function normally. This is why people with CDG have many health problems — because many body systems are affected by glycosylation not working correctly.

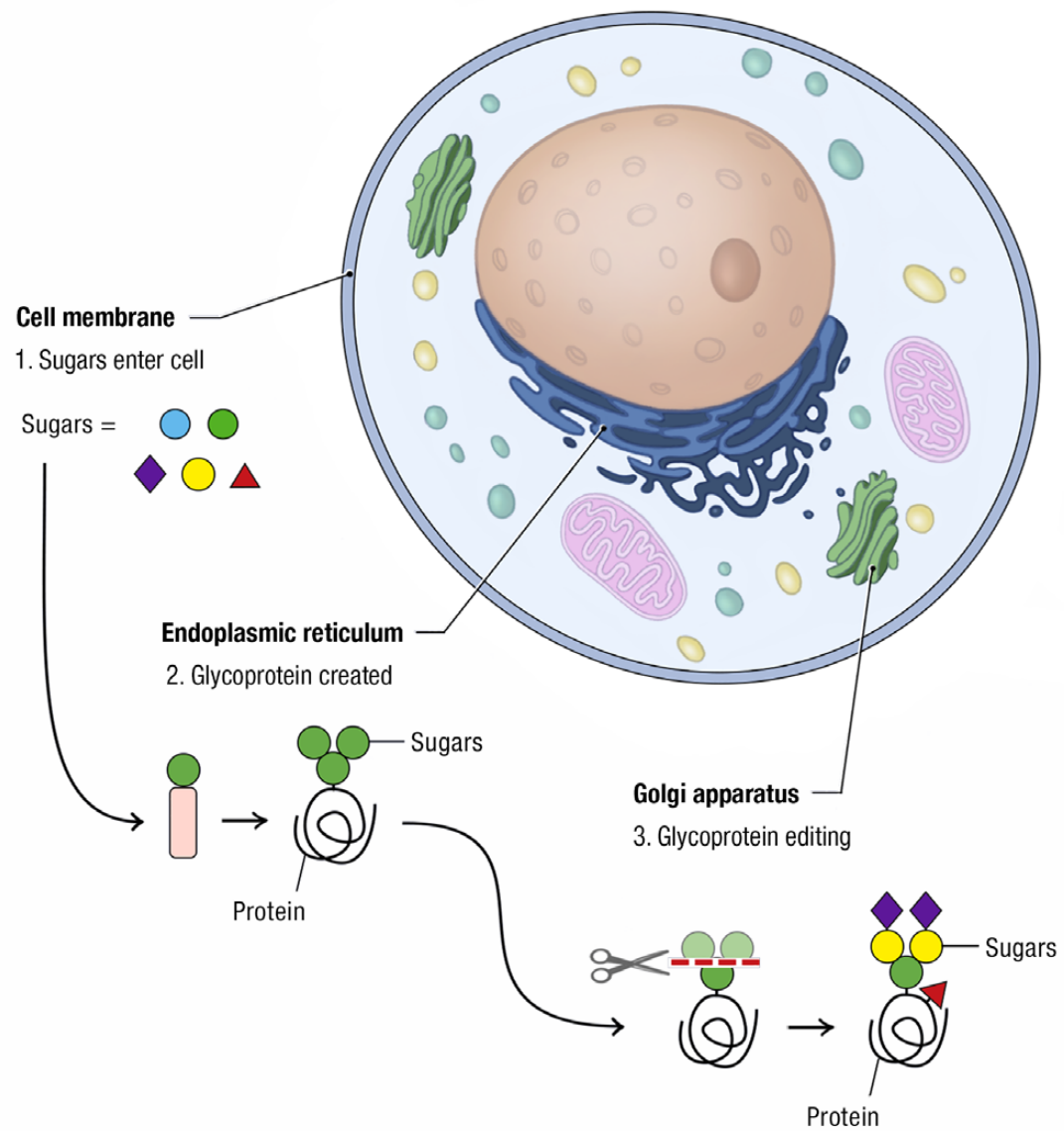


Figure 1. Normal glycosylation in a cell

Your Child's Health Care Team

Depending on your child's unique needs, he or she may need care from many medical specialists.

Over time, your child may have many appointments with his or her care team. After your child has been seen the first time, each provider usually recommends when the next follow-up visit will be.

Your child's health care team may include:

- A medical genetics specialist.
- Genetic counselors.
- A primary care pediatrician.
- Nurse practitioners and special nurses.
- Neurologists.
- Physical therapists (PT).
- Occupational therapists (OT).
- Speech language pathologists.
- Registered dietitians.
- Gastroenterologists.
- Endocrinologists.
- Cardiologists.
- Vision specialists, called ophthalmologists.

Depending on your child's unique health concerns, the team may also include:

- Liver specialists, called hepatologists.
- Coagulation and blood disease specialists, called hematologists.
- Orthopedic specialists.
- Infectious disease physicians, called immunologists.
- Hearing specialists, called audiologists.
- Ear, nose and throat specialists.
- Financial representatives.
- Social workers.

Your child's health care team works together to provide supportive care for your child and help him or her make the most of his or her abilities. Know that you and your child are the most important members of this team.



"Build a health care team you trust, a team that understands the complexity of your child's health, that listens to others, that understands the rarity of your child's disease and knows that your CDG child is unlike most kids, that your child will present symptoms in a way that a typical child would not. Find a team of doctors that will fight for the answers, be thorough and compassionate."

Symptoms of CDG

Symptoms vary depending on the type and sub-type your child has. They also vary among family members with the same type. Symptoms can range from mild to severe.

CDG can affect every body system. Which symptoms and complications your child has depends on which systems are affected.

Because the condition is very rare, only a few people have each type and sub-type. This makes it hard for health care providers to have a complete list of symptoms. Not everyone has every symptom.

Some children have serious medical conditions which can be life-threatening. Your child may be in the hospital often and for long stays.

Neurological problems

- Developmental delays, such as talking and walking later than others
- Cognitive impairment
- Seizures
- Poor balance and coordination problems, called ataxia
- Slurred speech, called dysarthria
- Crossed eyes, called esotropia

Growth problems

- Feeding difficulties leading to slow weight gain, called failure to thrive
- Delays in getting taller or gaining weight

Problems related to your child's organs not working as they should

- Gastrointestinal symptoms, such as throwing up and diarrhea
- Liver problems
- Heart problems

Endocrine problems

- Decreased thyroid hormone activity, called hypothyroidism
- Low blood sugar due to high insulin levels, called hypoglycemia or hyperinsulinism
- Growth hormone deficiency

Skeletal and joint problems

- Curvature of the spine, called scoliosis
- Joint problems

Hematologic problems

- Blood clotting problems, such as increased bleeding
- Increased risk of forming blood clots, called thrombosis

General problems

- Severe or long-lasting infections
- Swelling of the skin and fluid collection around the organs

"Do not compare your child to others, even ones who do not have CDG."

Cause of CDG

To understand the cause of CDG, it can help to understand some basic concepts about genes and heredity.

What are genes?

Most people have 46 chromosomes in all their cells. Each chromosome is made up of a long chain of a chemical called deoxyribonucleic acid (DNA).

A gene is a section of one of these DNA chains. See Figure 2.

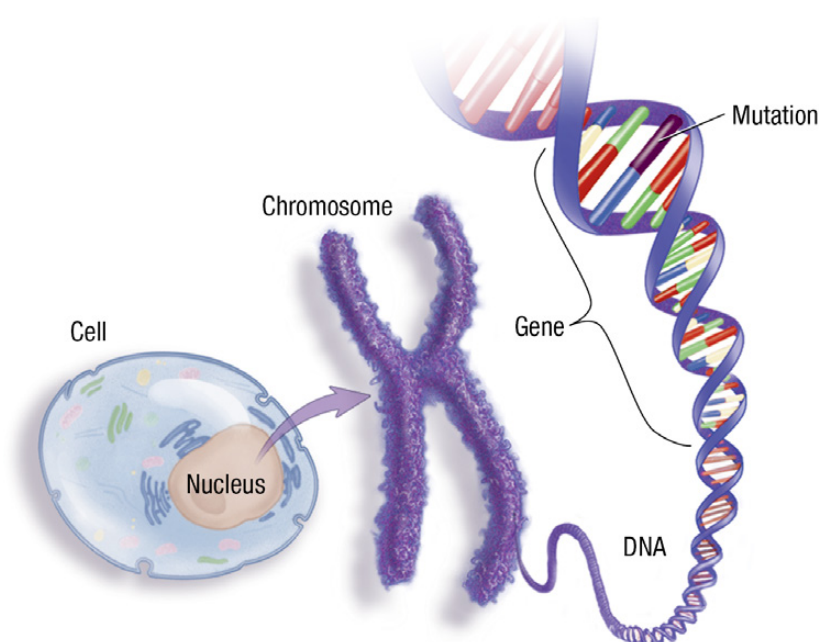


Figure 2. Each cell has chromosomes in its nucleus. Chromosomes are long chains of DNA that contain genes.

Everyone is unique because of their genes. Genes are like an instruction book that tells your cells how to work. For example, genes determine everything from your eye color to your blood type to your height.

CDG is caused by mistakes or changes in genes. Health care providers used to call these mutations. They are now called pathogenic genetic variants.

Pathogenic genetic variants are like words in a sentence that are spelled wrong or are in the wrong order. The sentence cannot be read correctly when this happens. Inherited genetic variants pass from a parent to a child. At birth, they are in every cell of a child's body. Genetic variants can be inherited from either the mother or the father.

Pathogenic genetic variants can keep cells from doing their work correctly, which can lead to genetic diseases like CDG. Genes determine how well the process of glycosylation works in your body. There are over 400 genes in the human genome that have a role in the process of glycosylation.

How CDG Types Are Named

Currently, over 150 types of CDG have been identified with new types being identified all the time. CDG types are grouped based on the sugar building blocks affected.

Children diagnosed with the same type usually have the same medical problems, but not always.

The largest CDG group is called the “N-linked” group. The N-linked group is divided into two types: type I and type II.

- In type I, sugar chains are missing.
- In type 2, sugar chains are incomplete or incorrect.

Health care providers used to name the types based on the pattern of the sugar building blocks, but that system became confusing.

Now providers use a system of naming the type using the official abbreviation of the name of the affected gene followed by “-CDG.” For example, one type is PMM2-CDG and another is PGM1-CDG.

Diagnosing CDG

CDG is usually diagnosed when your child is a baby. To diagnose CDG, your child's health care provider does a thorough physical exam and talks to you about your and your family's medical history.

Children with CDG are often mistakenly diagnosed with other conditions. This is because their symptoms are similar to symptoms of other conditions. Some are mistakenly diagnosed with cerebral palsy or other neurological or genetic disorders. An important part of diagnosis is ruling out other conditions.

Your child's health care provider may order these tests:

- Genetic testing, which is the most reliable way to diagnose CDG. Genetic testing can also determine the type.
- Blood tests to check for many things, including missing sugar building blocks on hormone proteins, coagulation factors, transport proteins, and elevated liver enzymes (ALT and AST).
- A transferrin glycosylation test, which is used to check for missing or incomplete sugar chains. Transferrin glycosylation results are often normal in many children with CDG. Special laboratory tests might be needed.



Additional tests

Depending on symptoms or problems your child has, you may be referred to specialists for tests of other conditions that are often associated with CDG.

Your child may have imaging exams done, such as liver ultrasounds, X-rays and MRI scans. Results of these can be used by your child's provider to plan treatment.

Overview of Treatment

Although there is currently no cure for CDG, there are many treatments and therapies available to help your child. The goal of these treatments is to treat the symptoms and the problems caused by the condition. This type of treatment is called supportive therapy.

Supportive therapy may include:

Physical therapy — A physical therapist (PT) can work with your child to develop muscle training and exercises that may help your child's strength, flexibility, balance, motor development, and mobility.

Speech therapy — Speech-language pathologists can help improve your child's ability to speak clearly or to communicate using sign language.

Occupational therapy — Occupational therapists (OT) can develop an exercise program for your child that includes stretching, strengthening, and functional use of the upper extremities.

A special diet — There are two CDG types where a diet that includes a special sugar supplement can help improve most symptoms.

- For the type called MPI-CDG, mannose can help.
- For the type called PGM1-CDG, galactose can help.

Other treatment may include:

- Seizure management.
- Nutrition care including tube feeding, if needed.
- Heart medication.
- Hormone supplements to treat growth problems.
- Antibiotics to treat or prevent infection.
- Organ transplants.

Next Steps

The next step for you is to learn more information about how your child's condition may be treated. You can also learn about how to help your child have the best life possible.

Talk to your child's health care team about next steps in your CDG journey.

"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."

Terms You May Hear or Read About CDG

Medical conditions can be complicated. Genetic conditions are especially complicated. CDG is even more so.

Here is a list of terms you are likely to read or hear. Understanding these terms can help you have good conversations with your child's health care provider.

Autosomal — Humans have 23 pairs of chromosomes. One pair determines which sex a person is. The other 22 are called autosomes.

Carrier — A person who has the gene for a condition or trait that can be passed on to his or her children.

Chromosomes — Any of the DNA-containing structures located in the nucleus of cells that contain all or most of the genes in an organism.

Congenital — Term used to describe a condition someone has from birth.

Enzymes — Complex proteins produced by cells that cause biochemical reactions.

Enzyme assay — A test that is done to measure a protein's activity to determine how efficient the protein is in biochemical reactions.

Failure to thrive — Term used to describe when a child does not gain weight as he or she should.

Gene — A coding sequence in the DNA. A specific mistake in a gene causes a specific disease.

Gene variant — Changes in the DNA code in a specific gene.

Genetic code — A DNA code written using four letters: A, T, C, and G.

Genetic — Relating to or caused by genes.

Glycoproteins — Sugar blocks attached to proteins.

Glycolipids — Sugar blocks attached to lipids.

Metabolism — The process by which your body converts what you eat and drink into energy.

Mutations — This term was previously used by providers to describe a mistake in genetic code. The new term used is pathogenic genetic variant.

Oligosaccharides — Sugar blocks assembled in a chain.

Pathogenic genetic variant — Mistake in the DNA code in a specific gene. This used to be called a mutation.

Prognosis — The anticipated or expected plan for healing or recovery.

Notes

Notes

Notes



BARBARA WOODWARD LIPS PATIENT EDUCATION CENTER

Mrs. Lips, a resident of San Antonio, Texas, was a loyal Mayo Clinic patient of more than 40 years and a self-made business leader who significantly expanded her family's activities in oil, gas and ranching. Upon her death in 1995, Mrs. Lips paid the ultimate compliment by leaving her entire estate to Mayo Clinic. By naming the Barbara Woodward Lips Patient Education Center, Mayo honors her generosity, her love of learning, her belief in patient empowerment and her dedication to high-quality care.

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.

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Learning About CDG

You have been given this resource because your child has been diagnosed with CDG. CDG stands for congenital disorders of glycosylation. Knowing that your child has this condition may worry you. You may feel overwhelmed right now and you may wonder what you can expect for your child.

You do not have to manage alone. Your child's health care team is here to help. Just by reading this information, you have taken an important step in caring for your child.

What you can do:

- Learn everything you can about CDG and how it may affect your child's daily life. Learning about CDG can help you advocate for your child's needs and make health care decisions.
- Learn about treatment options.
- Know the symptoms of health problems that may result from CDG and what to do if your child has symptoms.
- Understand how you and your family can take an active role in your child's health care.

This resource explains how you can help your child. It includes information about the members of your child's health care team, how CDG may be treated, how to know when your child is having symptoms of CDG complications, and how you can help your child have a good quality of life.

If you have questions about CDG, talk with your child's health care team.

Your Child's Health Care Team

Your child's health care team includes many health care providers who work closely together to support your child, you and your family. The health care team plans care tailored to your child's specific needs. The team works together to help you manage your child's symptoms and help your child make the most of his or her abilities.



Your child's health care team may include the following:

- **Medical genetics specialists** help with diagnosis, counseling, testing family members, and finding and organizing the treatment team for your child.
- **Genetic counselors** teach you about CDG, as well as provide counseling and testing of family members.
- **A primary care pediatrician** coordinates and provides routine childhood care.
- **Nurse practitioners and special nurses** have advanced education in a nursing specialty. These nurses provide guidance for nursing staff caring for your child. They can provide support to you and your family when your child is in the hospital.
- **Neurologists** diagnose and treat seizures, balance problems and stroke-like episodes (SLEs).
- **Physical therapists (PTs)** help strengthen muscles and improve movement affected by CDG.
- **Occupational therapists (OTs)** evaluate and treat your child for problems that limit his or her ability to do functional activities, such as dressing, bathing and going to school. OTs focus on fine and gross motor skills and the ability to swallow safely. OTs help your child be as independent as possible.
- **Speech language pathologists** help with speech therapy and problems with chewing or drinking.
- **Registered dietitians** evaluate your child's nutritional needs and help decide how best to meet those needs. This includes managing symptoms, promoting healthy growth and development, and preventing complications.
- **Gastroenterologists** diagnose and treat problems with diarrhea, constipation or vomiting.
- **Endocrinologists** diagnose and treat hormone and growth problems or low blood glucose levels.
- **Cardiologists** diagnose and treat heart problems.
- **Vision specialists, called ophthalmologists**, diagnose and treat vision problems.

Depending on your child's unique health concerns, the team may also include the following:

- **Hepatologists** diagnose and treat liver problems.
- **Hematologists** diagnose and treat bleeding or clotting disorders.
- **Orthopedic specialists** diagnose and treat bone and joint problems.
- **Infectious disease physicians and immunologists** review test results and work with team members to recommend vaccinations and medications to prevent and treat infections.
- **Hearing specialists, called audiologists**, evaluate your child's hearing and assess whether your child needs a hearing aid or other type of hearing support.
- **Ear, nose and throat specialists** help your child if he or she has hearing problems.
- **Financial representatives** can meet with you and answer insurance and other financial questions.
- **Social workers** support you and your child through your health care journey. They can refer you to community resources that will help you care for your child at home and also help you make financial plans.

Remember that you, your child and your family are the most important members of the team.



Treating CDG

Treatment is focused on managing symptoms and preventing complications caused by the condition. Treatment depends on which sub-type your child has, which body systems are affected, age, symptoms, and other health conditions. At this time, there is no cure for CDG.

Goals of treatment:

- Manage your child's symptoms
- Prevent complications
- Give your child the best quality of life possible

Listed here are complications your child may have and treatments that may help. This section is organized by body system.

Neurological

Poor balance and coordination, called ataxia: Physical and occupational therapy are the most important treatments for balance and coordination problems. Muscle training and exercises may help your child's strength, flexibility, balance, motor development, and mobility.

If it is hard for your child to stand or walk, your child's physical therapist can work with you and your child to identify equipment that may help, called adaptive equipment. Adaptive equipment includes standers, walkers, canes, wheelchairs, and lift systems.

Low muscle tone, muscle contractions and stiff muscles: Medications that can lessen muscle tightness may be used to improve functional abilities, treat pain, and manage complications related to CDG symptoms. Your child's provider may recommend injections of botulinum toxin on a regular basis, such as every three months.

Medication your child takes by mouth may also be used, such as baclofen (Gablofen™).

Stroke-like episodes (SLEs): Ensuring your child gets enough liquids and stays well-hydrated can help prevent SLEs. Treatment may include physical therapy to help manage effects of the episodes.

Seizures: Many different types of seizures occur in CDG. Treatment may include medications, hormones, dietary supplements, and diet changes.

Fevers can make seizures worse. Fever-reducing medication, such as acetaminophen, may be recommended. However, if your child has liver problems, it is important he or she is never given a higher dose than recommended.

Slurred speech: This is usually treated with speech therapy. Some children with CDG use a special device to communicate.

Crossed eyes: This is usually treated with surgery.

Gastrointestinal

Vomiting: Usually, providers recommend that your child gets the right amount of calories for your child's needs, if possible. Your child's provider may recommend the use of a special formula that is pre-digested.

Chronic diarrhea: Treatment with mannose in MPI-CDG can prevent diarrhea.

Protein-losing enteropathy: A diet rich in mid-chain fatty acids (MCT) and some medications can help prevent loss of protein.

Regular albumin infusions can help keep blood protein levels in balance. These can also help prevent fluid collection, called edema, under the skin and around vital organs.

Hepatic (liver)

Liver problems: Some children with liver disease are given sugar supplements. However, for most, no treatment is needed. Your child should be vaccinated for hepatitis A and B.

Cholestasis: This is usually treated with eating a special diet that includes fat-soluble vitamins — mainly vitamins K, D and E.

Liver cirrhosis: Your child's health care provider watches for the development of liver cancer, called hepatocellular carcinoma, and recommends treatment.

Hematologic (blood)

For all the possible blood problems, your child's provider may recommend:

- Watching for signs of blood clotting, including watching test results for PT, aPTT, factors I, VIII, IX, and XI, antithrombin, protein C, and protein S.
- Making sure your child gets the right amount of fluids and activity.
- Prescribing medications to prevent blood clots, also called blood-thinners, if your child has a blood-clotting problem. These medications include unfractionated and low-molecular-weight heparin, warfarin and rivaroxaban.
- Giving your child fresh frozen plasma therapy for surgeries and in case of bleeding.
- Giving your child sugar supplements for blood clotting problems.

Endocrine

Problems may include:

- Slow weight gain, called failure to thrive.
- Poor thyroid function that can result in growth delay and constipation.
- Problems with glucose metabolism.
- Low stress hormones associated with low blood sugar levels, called hypoglycemia.

For many of these problems, the treatment may be giving your child hormones in the form of medication he or she swallows. Treatment may also include a special diet.

High insulin levels associated with low blood sugar levels: This is usually treated with diazoxide.

Immune system

A possible problem is frequent infections. Infections may be treated with:

- Medications to treat infections, such as antibiotics, antivirals and antifungals.
- Immunoglobulins given through a tiny tube, called a catheter, inserted in a vein in your child's hand or arm. This is called an IV, which stands for intravenous.
- Diet changes.
- A bone marrow transplant if a child has severe immune system failure.

"Become a CDG expert. Familiarize yourself with the symptoms so you know what to watch for and can act quickly. Learn the medical terms so you can have meaningful conversations with medical professionals."

Your Child's Diet

Most children with CDG can eat a normal diet. However, some treatments that include diet changes or supplements can help with certain problems caused by CDG. These treatments are meant to increase the concentration of sugars for sugar-chain production.

Other treatments include adding trace elements in your child's body, which are important for the normal function of enzymes involved in glycosylation. Studies have shown these to be helpful with certain sub-types of CDG:

- Galactose, which your child swallows, has improved liver, blood and hormone disease in PGM1-CDG.
- Mannose, which your child swallows, has improved liver, gastrointestinal, blood and hormone disease in PGM1-CDG. However, for some children, this therapy causes significant side effects. One is damage to the red blood cells, called hemolysis. The other is a yellow tint to the skin and eyes, called jaundice. Jaundice is caused by an excess of bilirubin, a substance created when red blood cells break down. This condition is called jaundice.
- Galactose, manganese and uridine, which your child swallows, have led to better seizure control.
- Fucose, which your child swallows, has been found to have positive effects on immune symptoms and neurologic development in SLC35C1-CDG.

Other treatments

- If your child has low blood glucose levels, your child's provider may recommend he or she eats often. These meals need to include complex carbohydrates.
- Tube feeding to help meet nutritional needs.

About tube feeding

The medical term for tube feeding is enteral nutrition. When a child cannot eat or cannot eat enough, tube feeding can provide nourishment. During tube feeding, breast milk or formula passes into the digestive tract, that is, the stomach and small intestine, through a tube in your child's nose, mouth or an opening in his or her abdomen.

Breast milk or formula can be used for tube feedings. Sometimes your child may need a supplemental or specialty formula for healing and meeting his or her nutritional goals.

Your child's health care team lets you know if your child needs these. Your child's provider may recommend continuous or nighttime tube feedings. If your child needs to be tube fed, you will be shown how to do it.

As your child grows, his or her nutritional needs will change. Meet with a metabolic dietitian to learn how to help your child meet nutritional needs.



Health Care Concerns

Preventing infection

Most children with CDG do not have a greater risk of infection. However, when they do have an infection, it can be harder to recover.

Follow these guidelines:

- Handwashing is the single most effective way to prevent infection. Wash your hands thoroughly with warm, soapy water. Rub them for at least 15 seconds before you rinse. Always carry a small bottle of waterless hand sanitizer for you and your children to use when soap and water are not available.
- Keep your child away from people with active, contagious disease or illness, including those with cold or flu symptoms.
- If your child is exposed to measles or chicken pox, contact your child's health care provider for information about next steps.
- Any time your child is in the hospital, keep the door of your child's room closed.
- One of the first signs of infection is a fever. Do not ignore a fever. Seek medical care for your child within one hour if he or she has a temperature of 100.4 degrees Fahrenheit (38 degrees Celsius) or higher.

Vaccinations

Unless your child's health care provider tells you otherwise, your child should get age-appropriate vaccinations to help prevent infection and disease.

"Know your child's health history. When there are situations that you need to act fast, doctors and nurses can act quickly to find a solution."

Possible Complications of CDG

Your child with CDG has the risk of complications. Talk to your child's health care team about these possible complications and what you can do to prevent them. Here are some common complications of CDG, symptoms to watch for and what to do:

Possible complication: *Infection*

Symptoms: Temperature of 100.4 degrees Fahrenheit or higher, chills, not controlled by medication

What to do: Contact your health care provider immediately. Use physical cooling if needed to lower seizure risk.

Possible complication: *Thrombosis, which is a blood clot blocking a blood vessel*

Symptoms: A change in skin color or size of arms or legs

What to do: Seek emergency care.

Possible complication: *Seizures*

Symptoms: Repetitive shaking or stretching movements, chewing, nodding or jerking motions

What to do: Seek emergency care. If you have a seizure gel for rectal applications at home, use it immediately following the directions you have been given by your child's health care provider.

Possible complication: *Stroke-like episode*

Symptoms: One side of your child's face or body looks or acts differently than the other or your child is unable to move an arm, hand, leg, or foot.

What to do: Seek emergency care.

Possible complication: *Bleeding that does not stop within 5 minutes or loss of consciousness as a result of an accident*

What to do: Call 9-1-1 or seek emergency care.

Living Well With CDG

Having a child with CDG can bring many changes to your life and your family's life. Managing treatment and follow-up care may seem overwhelming to you.

Your child's health care team can help. Talk with them about how to manage the changes brought on by having a child with CDG. Team members can offer guidance and connect you with other support services.



Growth and development

Children with CDG share many of the same needs as healthy children. Talk to your child's health care team regularly to evaluate the progress of your child as he or she moves through various stages of growth and development.

Delayed milestones

New skills that children learn as they grow and develop are called milestones. These include:

- Gross motor skills, such as crawling or walking.
- Fine motor skills, such as picking up small objects.
- Speech and language.
- Social and cognitive skills, such as the ability to connect with others, reasoning and problem-solving.

Children with CDG may walk or crawl later than is typical for other children. It may take several years to know how well your child will walk or move. Your child needs regular follow-up visits with physical therapists and occupational therapists. Therapy can help improve your child's skills and mobility.

Learning problems

Some children may have cognitive impairments or specific learning disorders. As a result, a child may need special services at school. Learning needs should be assessed before your child starts kindergarten.

Record your child's milestones

You can help provide positive memories by recording important events, signs of progress, milestones, and funny stories.

Some ideas include:

- Establish a website to journal, communicate, and save memories and well wishes from friends and family. Ask a health care team member about using a computer if you did not bring one.
- Consider personal journaling, scrapbooking or picture-taking as a means of sharing memories with your child later in life.
- Keep a book of visiting friends and family and cards received.
- Take occasional hand-and-foot ink prints to show growth and progress throughout your child's life.
- Videotape interactions with your child and take pictures.

Emotional issues

Having a child with health issues can exhaust you. You may feel resentful, guilty or isolated. You may have physical signs of stress, such as fatigue, headaches and muscle aches.

Other parents of children with CDG have said they have felt the same way. The important thing to know is that you do not have to manage on your own and help is available.

Social workers, therapists, chaplains, and clinical nurse specialists help you understand your feelings. They can also help you adjust your and your family's lifestyle. Over time, you may settle into a comfortable routine.

Be sure to take care of yourself. If you don't take good care of yourself, you won't be able to take good care of your child.

Tips for taking care of yourself:

- Try to get enough sleep, exercise often and eat healthy.
- Take breaks from caring for your child to do something just for you, for your partner, and for your other children.
- Accept help from friends and family. When friends and family offer help, ask them to spend time with your other children. Suggest they bring meals if you need them. Ask for help with the laundry, shopping and other household chores.

If you have other children

Other children in the family may feel upset about their sibling's health struggles, and the extra attention he or she gets. Your other children may need one-on-one time with you. If possible, on a regular basis, arrange for another adult to care for your child with CDG while you spend time with your other children.

Other caregivers

While being with your child is important, it is just as important to take time to care for yourself. In addition, there may be times when you are just not able to care for your child, such as when you have a health issue yourself.

Identify other people who can care for your child. These caregivers can be a parent, a sibling, a neighbor, or a friend. Consider having more than one caregiver in case someone isn't available when you need them. Caregivers should be able to get your child to and from health care appointments and provide basic care in your absence.

As you consider people who might fill this role, think about:

- Who is trustworthy, responsible and dependable?
- Who is physically capable of providing care?
- Who would be comfortable spending time in a health care environment? Who can tolerate illness, blood and unusual smells?
- Who can take time off work or school when needed?

Be sure to explain what is needed so they have a clear understanding of your child's needs.

Talk to your child's health care team if you have trouble finding others who can care for your child. Having a good support system is important for both you and your child.

Daycare and school

It can be helpful for you and your child to spend time with other children, including those who don't have CDG as well as those who do. Going to daycare and later, to school, can offer those opportunities.

Talk to your child's health care provider about early intervention programs (EIPs) and special education classes. All states are required by law to offer early intervention programs for children from birth to 3 years old. Some states also offer special education classes for children between the ages of 3 and 5 years old. Ask your child's health care provider about special services that may be available.

Keeping your child safe

You need to set up a safe environment for your child when you are at home and when you are away from home.

Preventing injuries and harm is not that different for children with CDG than for children without CDG. Each child is different, and the general recommendations to keep children safe should be adapted to fit your child's skills and abilities.

To help keep your child safe:

- Know and learn about the unique concerns and dangers for your child.
- Once you have ideas about keeping your child safe, make a safety plan and share it with your child, your family, and other adults who might be able to help if needed.
- Remember that your child's needs for safety will change over time.

Think about the following things when you make a safety plan for your child:

Moving around

Children who have limited ability to move or make decisions might not realize that something is unsafe or they might have trouble getting away.

- Carefully evaluate the areas where your child spends time. Make sure the areas are safe.
- Check your child's clothing and toys. Are they suitable for his or her abilities, not just age and size? For example, clothing and toys that are meant for older children might have strings that are not safe for a child who cannot easily untangle themselves, or toys might have small parts that are not safe for children who are still putting toys in their mouths.

Car safety

In addition to choosing a car seat that is age-, weight-, and height-appropriate, consider whether your child has difficulties sitting up or sitting still in the seat. Your child may need something different than a traditional car seat, as he or she gets older, depending on his or her ability to sit independently.

Talk to your child's health care provider or a child passenger safety specialist about the best type of car seat or booster seat and the proper seat position for your child.

Safety equipment

Examples of special safety equipment include hand rails and safety bars that can be put into homes to help a child who has difficulty moving around or a child who is at risk for falling.

Communicating about safety

Children who have problems communicating might have limited ability to learn about safety and danger. Try to find different ways to teach your children about safety such as:

- Showing them what to do.
- Using pretend play to rehearse.
- Practicing on a regular basis.

Traveling

Your child may have a higher risk for developing blood clots. When people travel by plane, the risk of blood clots is higher due to long periods of time spent not moving. If you plan to travel, encourage your child to move at least once an hour. Make sure your child drinks or gets enough fluids to stay well-hydrated.

Before your trip, ask your child's health care provider:

- How to massage your child's arms, hands, legs, and feet to encourage circulation and prevent blood clots.
- About whether your child should wear elastic travel socks.

Family planning

People who have children with CDG have a higher risk of having another child with CDG. Talk with a genetic counselor about your specific risk.

Financial Concerns

Understanding what expenses are involved related to having a child with CDG can help you make decisions as you plan ahead.

One of the first things you can do to help get and stay organized is get a three-ring binder. Use the binder to:

- Record your child's medical identifier number(s), insurance company name and policy and group numbers, pharmacies you use, phone numbers for the billing office of the medical facilities your child receives care from, and social workers' names and phone numbers.
- Store your receipts.
- Estimate expenses.
- Take notes about the conversations you have related to financial aspects.

Some facts about expenses:

- Many insurance programs and companies require you to get approval before having some medical procedures, called preapproval.
- Not all medical costs are covered by insurance.
- Ongoing costs include regular medical appointments as well as the cost of regular trips for health care. These may include travel, parking and lodging expenses.
- Your child may need to take certain medications. These medications can be expensive and may not be completely covered by insurance.
- You are ultimately responsible for all charges related to medical care not covered by insurance. Most health care organizations submit all charges to your insurance company. Any unpaid balance is your responsibility to pay. These balances are usually the result of your insurance co-pay, coinsurance and deductibles.

If your child is covered by Medicaid, you may be able to receive financial assistance for meal and lodging expenses when you travel. Call your county's social services department and ask to speak to a county financial worker to find out more. Ask if you need preapproval to qualify.

Steps to take:

- Talk to a financial coordinator or social worker about resources to help you meet the costs of your child's care.
- If you work, find out from your company's human resources department if you have disability benefits. Some employers provide short- and long-term disability, which covers some of your salary when you can't work.
- Set up as many automatic services in your life as possible, such as online bill payment.
- Meet with an accountant. Some expenses may be tax deductible. Find out what sort of expenses qualify and what you need to do to get credits or deductions.
- Consider private fundraising as a way to help meet expenses. Some organizations provide help in planning benefits and other fundraising activities.
- If you receive financial help from Medicaid or Social Security Disability, your coverage may be affected by your employment status. When you are ready to return to work, check with the agencies about how your coverage will be affected.

If you have questions or concerns, talk with a social worker and a financial representative from the health care facility where your child receives care.

Follow-Up Care

Children with CDG need long-term care by a medical care team. How often you bring your child in for follow-up care depends on your child's needs, age, symptoms, and abilities. Your child will probably have appointments with a primary care provider several times a year. You likely will bring your child once a year for appointments and tests with specialists.

It is very important you take your child to all regularly scheduled follow-up appointments. These visits are a way for your child's health care providers to monitor your child's health and development.



Bring to your child's follow-up appointments:

- A list of your child's medications, including dosages.
- A list of problems or challenges your child has been having as well as your own questions and concerns.

Over time, your child may have many appointments with the care team. During follow-up appointments, a health care provider examines your child. The provider may order tests. Use this time to talk to your child's provider about problems he or she is having and about questions you have.

After each appointment, your health care team recommends when the next appointment should be. Ask your child's provider whether follow-up appointments are scheduled by a team member or whether you need to do that.



Resources

Consider joining a support group, which may help you in many ways. It can be helpful to talk with others who understand the challenges — and rewards — of having a child with CDG.

Remember that the internet can be a wonderful tool for finding information on almost any topic. Unfortunately, not all health information on the internet is reliable. Be sure to evaluate the health information you find on the internet. Ask your child's health care provider where you can find good information.

For more information, ask your child's provider to suggest websites that have reliable information. Your health care provider cannot guarantee the accuracy of the information on websites. However, your child's provider can direct you to some that are likely to be reliable.

"Share your story with others. Be the one to talk about it first, answer the difficult questions and smile at all the concerning stares. The more you talk about it, the more you make your vulnerability known, and the easier talking about your child's condition is going to be for you."

Final Thoughts

Rely on your team of care professionals.

You'll need to make important decisions about your child's treatment. A team, coordinated by your health care provider, may include social workers, teachers and therapists, who are all familiar with CDG and able to help explain the resources in your area. Ask if the team includes a case manager or service coordinator who can help access financial services and government programs in your community or county.

Find other families of children with CDG.

Other families may have helpful advice. Some communities have support groups for parents and siblings of children with disabilities or who have chronic illnesses.

Keep records of visits with health care and service providers.

Your child may have visits, evaluations and meetings with many people involved in his or her care. Keep an organized file of these meetings to help you decide about treatment options and to help you monitor progress.

Stay current on new technologies and therapies.

Researchers continue to explore new approaches to help children with CDG.

Your child is special in so many wonderful ways. Yes, there will be challenging times ahead, but there will also be many joyful moments. And remember, at all times, your child's health care team is here to help you.





BARBARA WOODWARD LIPS PATIENT EDUCATION CENTER

Mrs. Lips, a resident of San Antonio, Texas, was a loyal Mayo Clinic patient of more than 40 years and a self-made business leader who significantly expanded her family's activities in oil, gas and ranching. Upon her death in 1995, Mrs. Lips paid the ultimate compliment by leaving her entire estate to Mayo Clinic. By naming the Barbara Woodward Lips Patient Education Center, Mayo honors her generosity, her love of learning, her belief in patient empowerment and her dedication to high-quality care.

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.

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MC8442-01



PATIENT EDUCATION

*A Message for Parents of
Children With CDG*

MAYO CLINIC CHILDREN'S CENTER



BARBARA WOODWARD LIPS
PATIENT EDUCATION CENTER

Mayo Clinic Children's Center

For more than 100 years, teams of physicians have cared for children at Mayo Clinic.

T. DENNY SANFORD PEDIATRIC CENTER

MAYO EUGENIO LITTA CHILDREN'S HOSPITAL

Pediatric Sub-Specialties in the following areas:

Allergy and Immunology	General Pediatric and	Plastic and Reconstructive Surgery
Anesthesiology	Adolescent Medicine	Psychiatry and Psychology
Cardiology	Gynecology, Adolescent	Pulmonology
Cardiovascular Surgery	Hematology and Oncology	Radiation Oncology
Child and Family	Infectious Diseases	Radiology
Advocacy Program	Medical Genetics	Regional (Health System)
Community Pediatrics and	Neonatal Medicine	Pediatrics
Adolescent Medicine	Nephrology	Research
Critical Care	Neurology	Rheumatology
Dermatology	Neurosurgery	Sleep Medicine Center
Developmental and	Ophthalmology	Speech Pathology
Behavioral Pediatrics	Oral and Maxillofacial Surgery	Surgery
Emergency Medicine	Orthopedic Surgery	Urology
Endocrinology and Metabolism	Otorhinolaryngology (ENT)	
Gastroenterology and Hepatology	Physical Medicine and Rehabilitation	

Pediatric Specialty Clinics:

Adrenoleukodystrophy Clinic	Dana Child Developmental and	Metabolic Bone Clinic
Aerodigestive Clinic	Learning Disorders Program	Mood Disorders Clinic
Anxiety Disorders Clinic and	Dermatology Genetics Clinic	Neonatal Follow-Up Clinic
Intensive Therapy Program	Diabetes Clinic	Neuromuscular Clinic
Arrhythmia and Device	Eating Disorders Clinic	Pain Clinic
Placement Clinic	Eosinophilic Esophagitis Clinic	Pain Rehabilitation Center
Asthma Center	Epilepsy Clinic	Pediatric Diagnostic Referral Clinic
Attention Deficit Hyperactivity	Erythromelalgia Clinic	Pediatric Level 1 Trauma Center
Disorders (ADHD) Clinic	Facial Paralysis and	Plagiocephaly Program
Bariatric Surgery Clinic	Reanimation Clinic	Pulmonary Hypertension Program
Brain Injury Program	Feeding Program	Renal Stone Clinic
Brain Tumor Clinic	Fertility Preservation	Spina Bifida Clinic
Cerebral Palsy Clinic	Fetal Surgery Program	Spinal Deformities Clinic
Chemotherapy/Radiation	Friedreich's Ataxia Clinic	Sports Medicine Center
Long-Term Effects Clinic	Functional Movement	Thyroid Nodule/Cancer Clinic
Child and Adolescent Intensive	Disorder Program	Transgender Clinic
Mood Program (CAIMP)	Heart Failure Clinic	Transitions Program
Childhood Sarcoma Clinic	Hemophilia/Coagulopathy Clinic	Transplant Center
ComPASS (Palliative Care and	Hyperlipidemia Program	Travel Clinic
Integrative Medicine)	Immunodeficiency Disorders Clinic	Vascular Malformations
Congenital Heart Clinic	Inflammatory Bowel Disease Clinic	Velo-Pharyngeal
Constraint Induced Movement	Learning Disorders	Insufficiency Clinic
Therapy Program	Assessment Clinic	Voiding Clinic
Craniofacial Clinic	Long QT Syndrome Clinic	Weight Management Clinic
Cystic Fibrosis Center	Marfan Syndrome Clinic	

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."



Notes

Notes



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MC8442-02