



Cristina,  
X-linked  
carrier  
of CGD

## THE X-LINKED CARRIER'S

# handbook

Understanding what it means to be a chronic granulomatous disease (CGD) carrier, empowering your family, and feeling supported

# Dear fellow CGD mom,

Welcome to a unique kind of sisterhood—one filled with a lot of medical appointments, keeping track of medicines, caring for a child with CGD, and the daunting task of balancing it all as an X-linked carrier of CGD. It's a club none of us chose to join and one that most people don't really understand.

But, **we get it:**

- **Emotions**—Those that weigh on our mental health
- **Stress**—From all of the responsibility of caring for a loved one with CGD
- **Education**—Empowering ourselves with the right information
- **Speaking up**—Finding our voice and advocating for our child and other family members
- **Isolation**—From no one understanding our journey
- **Not putting yourself first**—Finding the strength to act as a caregiver, even as we may experience carrier symptoms

It's a lot, to say the least. Yet, from all this, a group of X-linked CGD carriers, including me, put our heads and hearts together to help create this handbook for you. It's meant to:

- Help **validate** what you're going through
- Let you know **you're not alone** and that there's support available
- Help bring the focus back to **your medical and emotional needs**, knowing that you're vital to your family's well-being
- Provide helpful **information and tips** to help support and empower you as an X-linked carrier of CGD

Whether you're just learning about your carrier status or are well into your family's CGD journey, I hope you find this handbook helpful, including the "Your care checklist" on page 11 that gives you practical steps to navigate your carrier journey.

Thank you for being the strong woman that you are and, remember, we're here for you whenever you need us! Wishing you all the best and rooting for you and your family.

Warmest regards,

*Cristina*

X-linked carrier and mother of Liam, who was born with CGD

**Please review the Important Safety Information on pages 13 and 14 and the accompanying Full Prescribing Information and Information for the Patient/Caregiver and discuss with your doctor.**



*p.s.*

I invite you to take part in upcoming CGD community events that focus on X-linked carriers like us.



Email [CGDpartners@horizontherapeutics.com](mailto:CGDpartners@horizontherapeutics.com) for more information



As caregivers, we put ourselves on the back burner over and over again. It's as if you are swiping a credit card every time you put yourself on the back burner and you end up with a long bill of emotional tolls.

*Elisha*

X-linked carrier of CGD

Please review the Important Safety Information on pages 13 and 14 and the accompanying Full Prescribing Information and Information for the Patient/Caregiver and discuss with your doctor.

## As an X-linked carrier of CGD, you may not be “just a carrier”

In addition to the emotional journey that comes with a loved one's CGD diagnosis, you may also have days when you don't feel well yourself. You may experience symptoms that require monitoring and potential treatment.

Which of these symptoms have you experienced?

### Lupus-like/autoimmune issues

- Skin rash or infection
- Sensitivity to the sun
- Pain and swelling in the joints
- Feeling tired all the time
- Weight loss



### Gastrointestinal issues

- Diarrhea
- Vomiting
- Bloody stool
- Abdominal pain/cramps



### Mouth ulcers

### Thyroid problems

### Infections

Other: \_\_\_\_\_

### None



Often, mothers learn that they are carriers of CGD through their child's diagnosis. That news can feel devastating and, as a result, you may feel a variety of **emotions—including guilt, anxiety, or sadness.**

### Want to learn more about being an X-linked carrier of CGD?



- If your child is enrolled in Horizon By Your Side:  
Call, text, or email their Clinical Nurse Educator (CNE)
- If your child is not enrolled in Horizon By Your Side:  
Call the CGD Nurse Advocate Call Center at  
1 (833) 3-4MYCGD or start by speaking with your child's doctor

## Understanding your risks as an *X-linked carrier*

**Up to 23% of X-linked carriers may experience significant infections which, if left untreated, may become life-threatening.** Over time, your immune system may change and may begin working less effectively, which may increase your risk of CGD-related serious infections.

UP TO  
**23%**

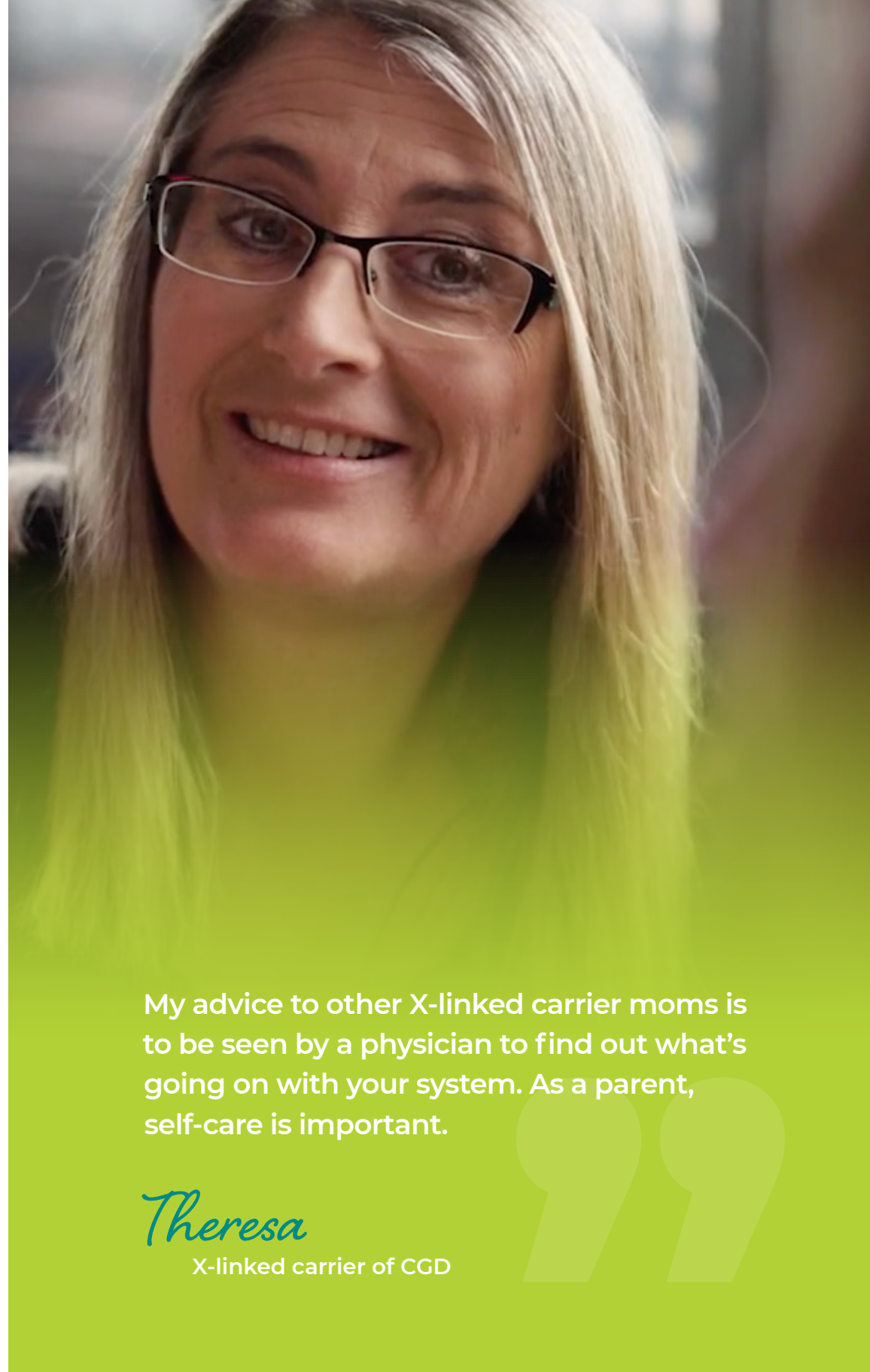
### Speak to a **CGD Specialist** about being evaluated

A CGD Specialist is often an **allergist or immunologist** who can help you create a plan to be evaluated, monitored, and potentially treated for any symptoms you may be experiencing as an X-linked carrier of CGD.



**If you don't know where to start, speak with your child's doctor. They may be able to guide you in the right direction.**

**Please review the Important Safety Information on pages 13 and 14 and the accompanying Full Prescribing Information and Information for the Patient/Caregiver and discuss with your doctor.**



My advice to other X-linked carrier moms is to be seen by a physician to find out what's going on with your system. As a parent, self-care is important.

*Theresa*

X-linked carrier of CGD

## Empower yourself and your family

*by understanding testing*

### The importance of **DHR testing** as an X-linked carrier

There's a blood test called a **dihydrorhodamine (DHR) test** that you and all X-linked carriers of CGD should know about, whether you're symptomatic or not.

#### A DHR test can help:

- Determine how well your cells are able to kill bacteria and fungi
- Assess/identify your risk for serious infection
- Monitor potential changes over time—**your DHR values can change as you age**
- Guide your doctor's treatment decision

Your first DHR test will establish a baseline value. From there, your doctor will monitor your condition and may recommend additional testing as needed.

My DHR test was done on \_\_\_\_\_ with \_\_\_\_\_ results.

I have never had a DHR test

### What do your **test results** mean?

The most important takeaway from your DHR test results will be your % DHR positive rate. Having a % DHR positive rate of:

**less than 20%** = a significant risk of serious infection

**less than 10%** = an even higher risk of serious infection

Talk to your doctor about your overall health and risk for infection.

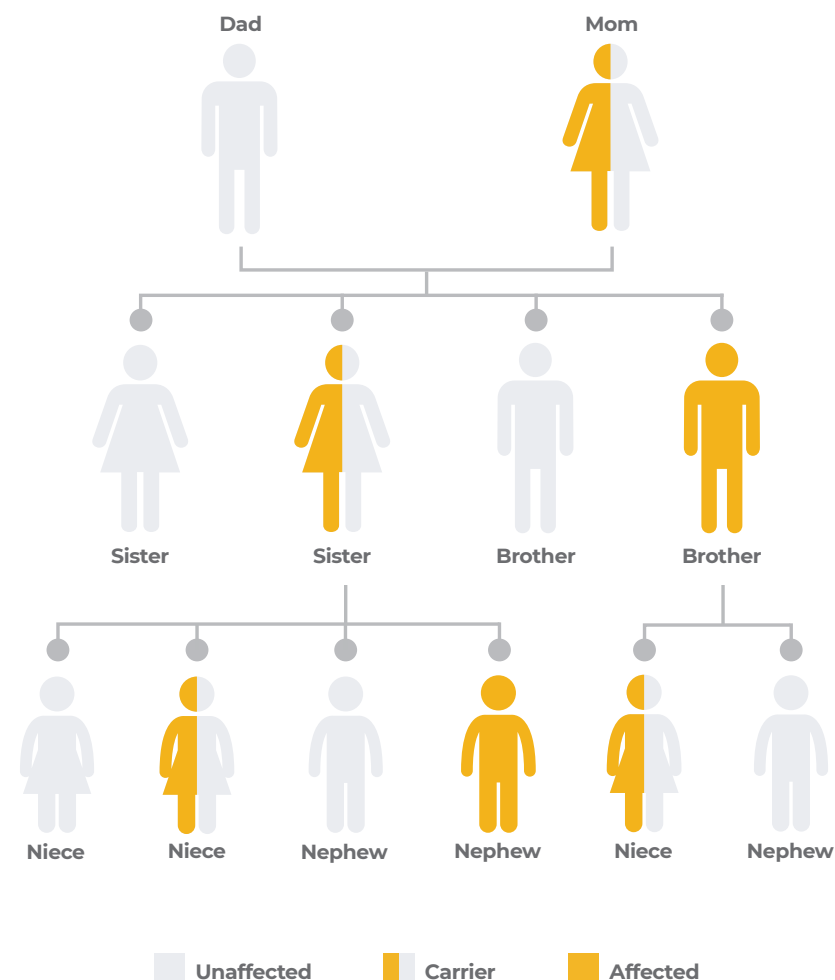
Please review the **Important Safety Information** on pages 13 and 14 and the accompanying **Full Prescribing Information** and **Information for the Patient/Caregiver** and discuss with your doctor.

## Don't forget about the importance of **genetic testing**

Your doctor may also wish to order a genetic test, which can:

- Confirm your diagnosis as an X-linked carrier of CGD
- Help guide or alter potential treatment options

Genetic testing is a great opportunity to help your family and extended relatives understand their own potential risk. **You might be the voice of encouragement they need to get started!**



**Talk to your doctor about testing options for CGD and how to be evaluated over time.**



If you have a child that is newly diagnosed with CGD, it's important that you get genetic testing to see if you're a carrier or not, and to encourage your extended family to get tested.

*Doris*

X-linked carrier of CGD

Please review the Important Safety Information on pages 13 and 14 and the accompanying Full Prescribing Information and Information for the Patient/Caregiver and discuss with your doctor.

## Your care checklist

Being a CGD caregiver is a big responsibility. Often, all of your spare energy and time goes into caring for a family member experiencing the challenges of CGD. In order to provide your family with the best care possible, it's important to recognize that you must also **take care of yourself**. It's okay to take time to monitor your own condition, including prioritizing your mental health and well-being!

Make a commitment to carve out time and work on checking off these items for better health:

- Take time for self-care—rest, recharge, and remember: "It's not selfish!"
- Learn how you may be at risk for serious infection
- Find a CGD Specialist to oversee your medical care (start by talking with your child's doctor)
- Have DHR testing done—whether you're symptomatic or not
- Make a plan with your doctor to monitor your medical status
- Talk to your immediate and extended family (sisters, aunts, cousins, etc) about the importance of testing
- Find support from family, friends, and the CGD Connections® community

## Learn more about being an X-linked carrier:



Visit [Facebook.com/CGDConnections](https://www.facebook.com/CGDConnections)



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

**Tear out this page to bring to your next appointment with your doctor or CGD Specialist.**



## The X-linked carrier's guide to talking to your doctor

Helpful questions to start a discussion with your or your child's doctor

I first experienced symptoms: \_\_\_\_\_

X-linked carrier symptoms I've experienced or currently have (see page 5 for common symptoms): \_\_\_\_\_

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If speaking with your child's doctor:

- Can I see you for my care as well?
- If not, can you help me find a doctor or CGD Specialist?
- What other types of specialists might I need to include on my own care team?

What tests can measure how well my immune system is functioning?

- How can I get a DHR test?
- Can you explain what my DHR test results mean? If not, who can help explain the results to me?
- Should I also get a genetic test?
- If I need to be tested, who else in my family should be tested?

If I'm at risk for serious infection, what are the next steps I need to take?

- What are some things I can do to lower my risk for infection?
- What are my treatment options?
- How will my medical condition be monitored over time?



**Talk to your doctor about no-cost DHR and genetic testing options for you.**

Please review the Important Safety Information on pages 13 and 14 and the accompanying Full Prescribing Information and Information for the Patient/Caregiver and discuss with your doctor.

## 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.

## Important Safety Information (Continued)

### 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](http://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 review the accompanying Full Prescribing Information and Information for the Patient/Caregiver and discuss with your doctor.**





Casey,  
lives with  
X-linked  
CGD

Ronald,  
Casey's  
father

Doris,  
X-linked  
carrier  
of CGD

Learn more about being an X-linked carrier:



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