

PROGNOSIS

The prognosis depends on each individual's disease and response to treatment. The disease course may be different depending on the patient. For many patients with appropriate treatment, the disease may go into remission; for others, the disease may persist. Some may need to stay on medications for many years. Others may be able to stop the medications altogether. This is why it is important to continue seeing your rheumatologist.

COMORBIDITIES

Possible comorbidities may include:

- ◆ Psoriatic arthritis
- ◆ Rheumatoid arthritis
- ◆ Inflammatory bowel disease:
 - ◆ Crohn's Disease
 - ◆ Ulcerative colitis
- ◆ Palmoplantar Pustulosis
- ◆ Psoriasis

PAIN MANAGEMENT

Physical and occupational therapy may help regain muscle strength and joint mobility once tolerated. When the disease is active, the therapy should be gentle and can be more involved once the disease is properly controlled. Warm or cold compresses may help at the lesion site as well as light massage.

SUPPORT

Being diagnosed with a chronic disease can be stressful. There are many support tools available, including a private Facebook support group, Kaila's Komfort, and the CRMO Foundation. The CRMO Awareness website has useful resources including 504 plans, research articles and a list of CRMO centers.

There is a CRMO Patient Registry hosted at the Coordination of Rare Diseases at Sanford (CoRDS) to better understand and research the nature of the disease as well as its progression. Please visit the CRMO Foundation website to learn more and sign up.

Additional Resources



www.crmoawareness.org

Created by a team of pediatric rheumatologists, this website has useful information about the disease, treatment, and support.



www.crmofoundation.org

The CRMO Foundation is a 501(c)(3) nonprofit organization whose mission is to support and improve the health and well-being of CRMO patients and their families by furthering the efforts of life-changing research, increasing access to resources and education and promoting awareness of the disease.



www.kailaskomfort.org

Kaila's Komfort is a 501(c)(3) nonprofit organization providing support to children and adults diagnosed with CNO. They ship free care packages around the world to kids and adults with CRMO/CNO and their families.



www.facebook.com/groups/CRMOawareness/

The CRMO Facebook site is a closed group for patients and families to ask questions, read stories and gather information in a safe and compassionate environment.



Chronic Recurrent Multifocal Osteomyelitis

Chronic Non-bacterial Osteomyelitis

What is Chronic Recurrent Multifocal Osteomyelitis?

Chronic Recurrent Multifocal Osteomyelitis (CRMO), also known as Chronic Non-bacterial Osteomyelitis (CNO), is a rare, autoinflammatory bone disease of unknown etiology. It involves inflammation of one or more bones and may persist for months or even years.

In a properly functioning system, inflammation is a normal process and is the immune system's way of protecting the body from infections and germs. This inflammation causes pain, redness, and swelling. However, in CRMO, there is no infection. The immune system wrongly attacks normal bone and causes inflammation.

CRMO/CNO is treated by a rheumatologist, though you may have a team of doctors consulting.



DIAGNOSIS OF EXCLUSION

CRMO can only be diagnosed once other diseases are ruled out, including malignancy and infectious osteomyelitis. Generally, many tests are required for a proper diagnosis, such as blood tests, X-rays, bone scans, MRI, and often a bone biopsy. CRMO patients often go years without a correct diagnosis and treatment. For this reason and because the disease is not well known, most primary care doctors, pediatricians, and ER physicians have never even heard of CRMO much less understand how to treat it.

Find a doctor with experience treating patients with CRMO. CRMO is generally treated by a pediatric rheumatologist or adult rheumatologist. Ask your doctor for a referral. The goal is to find the right medications to stop inflammation and heal the affected bones.

CAUSE

The cause of CRMO/CNO is unknown, however current research suggests genetic and/or environmental factors may play a role.

TREATMENT GOALS

- ◆ Decrease pain
- ◆ Reduce inflammation
- ◆ Prevent bone damage and bone deformities (for example: fractures, leg length discrepancies, changes in spine curvature)
- ◆ Help to avoid growth issues

MEDICAL INTERVENTION

CRMO/CNO is unique for each individual. The goal of treatment is to reduce the inflammation and pain in the body so anti-inflammatory and immunosuppressive medications are used. Several different types of medications may be tried before finding something that works. In certain cases, doctors may combine medications to treat the disease. For some CRMO/CNO patients, the disease can be managed with nonsteroidal anti-inflammatory drugs (NSAIDs). NSAIDs are usually the first line treatment. However, if NSAIDs are not effective or tolerated well, second line treatments are available. In some cases, your doctor may use a short course of corticosteroids to reduce inflammation. These medications are also used to treat other rheumatologic and inflammatory conditions. Below is a table of medications that may be prescribed.

NSAIDs	Additional Medications
Naproxen (Aleve®)	Methotrexate (Otrexup®, Rasuvo®, Trexall®)
Celecoxib (Celebrex®)	Sulfasalazine (Azulfidine®)
Meloxicam (Mobic®)	Leflunomide (Arava®)
Piroxicam (Feldene®)	Pamidronate (Aredia®)
Indomethacin (Indocin®)	Zoledronic Acid (Zometa®)
Diclofenac (Voltaren®)	Adalimumab (Humira®)
	Etanercept (Enbrel®)
	Infliximab (Remicade®)

TREATMENT PLAN

Once on an effective treatment plan, you should begin to feel better, although some treatments may take a while to take effect. CRMO/CNO is a chronic unpredictable condition where symptoms may come and go for years. You may achieve remission or you may develop inflammation in other bones sometimes without any symptoms. For this reason, your doctor may want to monitor your progress even if you are feeling well.

It is important to attend all of your appointments so bone inflammation or issues with the medications can be monitored. Since there are currently no known lab tests for CRMO/CNO, whole-body MRI is recommended to monitor disease progression. If whole-body MRI is unavailable, your rheumatologist may order an MRI of specific sites (such as an ankle or collar bone) or a nuclear medicine bone scan. A bone scan is not as sensitive as an MRI but can give an overall general picture as a baseline.



TREATMENT EFFECTIVENESS

- ◆ Pain reduction
- ◆ Ability to return to normal activities
- ◆ Labs tests showing improvement of inflammatory markers (CRP, ESR)
- ◆ Resolution of lesions shown with MRI studies