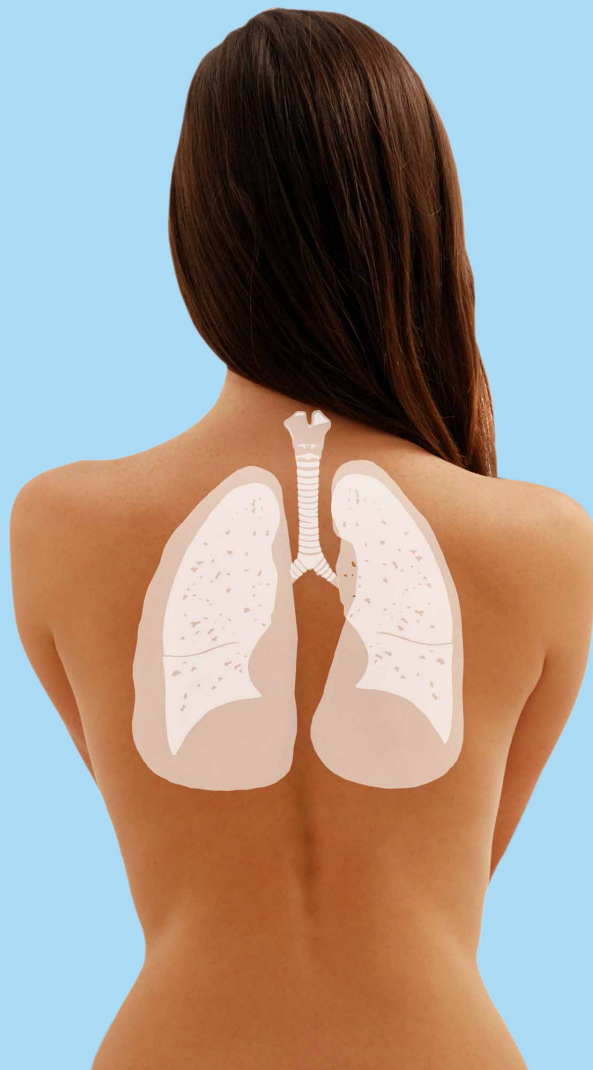


# *“insight”*



*a patient's perspective*



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NTM Info & Research

UPDATED  
for 2024

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## INSIGHT

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This pamphlet provides insight into infection and lung disease caused by nontuberculous mycobacteria (NTM), empowering patients to participate in their own treatment. NTM is also called atypical tuberculosis (atypical TB), mycobacteria other than tuberculosis (MOTT), *Mycobacterium avium* complex (MAC), or environmental mycobacteria (EM).

***This pamphlet contains condensed versions of the information on our website. You can read more about the topics covered here and much more by visiting [ntminfo.org](http://ntminfo.org) and [bronchiectasis.org](http://bronchiectasis.org).***

## WHAT ARE NONTUBERCULOUS MYCOBACTERIA?

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Nontuberculous mycobacteria (NTM) are naturally occurring environmental organisms found widely in both water and soil. They can cause or worsen significant respiratory damage, such as bronchiectasis (damage to the bronchial tubes of the lung), and they can also cause infection in skin, bone, and soft tissue, which can cause extensive damage and may lead to life-threatening sepsis. There are more than 200 species of nontuberculous mycobacteria. MAC or *Mycobacterium avium* complex, *M. kansasii*, *M. abscessus* complex, *M. chelonae*, and *M. fortuitum* are just a few. (“M.” is used as an abbreviation for mycobacterium.) Some are readily treated with two or three drugs, while other types are resistant to many drugs and more difficult to treat. These require treatment that is often more complex and of a longer duration.

## WHO GETS NTM?

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NTM lung disease (NTM pulmonary disease) is not as well-known or understood as tuberculosis (TB). There are certain underlying conditions (sometimes referred to as a comorbidity) that make some people more susceptible to NTM infection, such as prior lung infection, bronchiectasis, chronic obstructive pulmonary disease (COPD) and genetic diseases such as Cystic Fibrosis (CF), Alpha-1 antitrypsin deficiency, primary ciliary dyskinesia (PCD), and autoimmune pulmonary alveolar proteinosis (aPAP).

NTM lung disease in North America was seen predominantly in men and often misdiagnosed as TB. NTM lung disease then started to be seen more in slender Caucasian post-menopausal women and in men, younger women, and children. In other areas of the world including the Netherlands, the patient profile is quite different and is reported to be changing.

Autoimmune disorders such as Sjogren’s syndrome or rheumatoid arthritis (RA) may also increase someone’s risk of infection. Immunosuppressive medications such as chemotherapy, prednisone, or drugs used to treat conditions such as RA, psoriasis, and Crohn’s disease, may increase the risk of NTM infection.

NTM may cause infections in areas of the body other than the lungs (“extrapulmonary” or “disseminated”). These infections can occur in bone, skin, or soft tissue. Outbreaks of NTM have been reported and traced to nail salons, laser eye surgery centers, dental clinics, cosmetic procedures, and heater-cooler units used in open-heart (open-chest) surgery. Underlying immune deficiency from inherited disorders and illnesses such as Acquired Immune Deficiency Syndrome (AIDS) can also increase susceptibility to these types of infections.

Other underlying conditions include prior pneumonia, prior inhalation of inorganic dust, including silica, gastroesophageal reflux disease (GERD – which is spillage of material from the esophagus into the lungs), bronchiectasis, emphysema, or cigarette-induced lung disease.

Current estimates place the number of people with NTM lung disease as high as 220,000 people in the United States at any given time, with that number rising 8.2% each year in people 65 years and older. (Strollo et al., 2015)

## HOW DID I GET IT?

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NTM organisms are in the environment, including water (both natural sources and treated tap water) and soil. Doctors and scientists understand that some patients become infected with NTM from inhalation of mycobacteria that become aerosolized by showers, kitchen sink sprayers, indoor pools, hot tubs, or from refrigerator ice makers. You may wish to speak to your doctor about the advisability of bathing in a tub rather than showering. Some patients may become infected with NTM from inhalation of mycobacteria that are found in high concentrations in potting soil.

Skin and soft tissue NTM infections also occur with wounds, cosmetic procedures, or surgery when the area can be exposed to soil, water, or medical devices contaminated with NTM.

NTM infections are not only due to exposure to bacteria in the environment, but also because of host vulnerability.

## AM I CONTAGIOUS?

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No. NTM are not generally considered to be communicable person to person. Patients with certain comorbidities such as Cystic Fibrosis may be vulnerable to passing certain infections among each other, but it is uncertain whether NTM is one of them. For this reason, CF patients should take extra precautions when in close settings with one another.

## WHY HAVEN'T I HEARD OF NTM LUNG DISEASE BEFORE?

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You have probably heard of other mycobacterial diseases which are different than NTM lung disease. The two best known are *Mycobacterium tuberculosis* (TB) and *Mycobacterium leprae* (leprosy), both of which have caused great human suffering and are contagious.

Nontuberculous mycobacteria (NTM) should not be confused with TB or leprosy.

## HOW IS NTM DIAGNOSED?

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NTM infection is often misdiagnosed. Delayed diagnosis often makes treatment more difficult because of possible drug resistance and increased lung or tissue damage due to recurrent infections. Prior use of a single drug may have created drug resistance, which means that timely diagnosis and proper treatment is essential.

### The diagnosis of NTM involves the following:

**I. Sputum smear and culture** – Acid fast bacilli (AFB) smear and culture are the basic tests to identify mycobacteria. For accurate identification of the strain of NTM and drug sensitivities, testing should be done at a specialized laboratory. If you have difficulty coughing up sputum (mucus or phlegm), your doctor may decide to have you inhale medicine to induce sputum or perform a bronchoscopy to obtain the necessary sample.

**II. Chest CT** – A CT (CAT) scan is a three-dimensional image generated from a large series of two-dimensional x-ray images.

A CT scan provides the doctor with a detailed look at the extent and location of disease and is an important diagnostic tool. NTM diagnosis and follow-up generally requires a high-resolution CT scan **without contrast**. X-rays alone are insufficient.

**III. Medical History** – Knowing illnesses you and your blood relatives have had, including childhood illnesses, provides your doctor with information to understand why certain underlying lung conditions exist. When dealing with extrapulmonary or disseminated disease, it's important for your doctor to know of any recent incidents which may have caused skin punctures, including medical procedures or other surgeries. For more information on diagnostics and tips on gathering a family health history, visit **ntminfo.org**.

**IV. Tissue or Fluid Biopsy** – In the case of extrapulmonary or disseminated NTM infection, a biopsy of the tissue that is infected or a sample of the fluid in the area is collected and sent to a specialized lab for an AFB smear and culture. Because the causes of skin ulcers or lesions can often be misdiagnosed at first, identifying the pathogen in a timely manner is important.



## CYSTIC FIBROSIS

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Cystic Fibrosis (CF) is a progressive genetic disease that affects the lungs, pancreas, and other organs. CF patients have unusually thick, sticky mucus that clogs the airways and traps germs, including bacteria.

CF is a significant comorbidity for NTM lung disease. Some NTM patients are now being diagnosed with a form of CF as adults.

*For more information on Cystic Fibrosis, treatment guidelines and locations of accredited treatment centers, visit [ntminfo.org](https://ntminfo.org).*

## BRONCHIECTASIS

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Bronchiectasis is the most common and significant comorbidity that NTM patients typically have.

Bronchiectasis is a structural change of the airways which damages muscle or elastic tissue of the bronchial tubes. These dilated bronchial tubes develop pouches that can trap mucus. Bronchiectasis is not curable but can be managed.

It often begins early in life and may be misdiagnosed as chronic bronchitis or chronic obstructive pulmonary disease (COPD). You might not be diagnosed for many months or even years, often having had repeated lung infections and difficulty breathing.

If you are unable to clear the mucus because it is trapped in the damaged airways, infection can grow. As the damage progresses, infections, including NTM, can recur.

*For more information, visit [bronchiectasisinfo.org](https://bronchiectasisinfo.org) or [ntminfo.org](https://ntminfo.org).*

## COMMON SYMPTOMS OF NTM

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Patients with NTM infections often experience one or more of the following symptoms:

**1. Cough** – With or without mucus production.

**2. Hemoptysis** - NTM lung disease may cause you to cough up blood. If you cough up blood, you should seek medical attention immediately. Any time you cough up blood, it is essential that you remain calm and still to help minimize the amount of blood you cough up.

**3. Night Sweats, Fever** – You may experience a low-grade fever. The sensation of feverishness and sweating is often more prominent at night.

**4. Weight Loss (Loss of Appetite)** – Patients often report loss of appetite which results in weight loss. This should be discussed with your physician and/or a nutritionist to determine how to modify and augment your diet. Being underweight can affect your immune system and ability to fight NTM infection. You can also find a nutrition guide with suggestions for increasing caloric intake, as well as a printable food diary, at [ntminfo.org](https://ntminfo.org).

**5. Lack of Energy** – Many patients note a variable but often profound sense of fatigue.

**6. Feeling short of breath.**

**7. Wheezing.**

**8. Chest pain around the lung area.**

**9. Abscesses, ulcers, or lesions** (extrapulmonary).

Patients with extrapulmonary NTM infections may also experience fever, night sweats, and weight loss. In the case of skin, soft tissue, and musculoskeletal infections, you may have skin nodules or ulcers and wounds with abscesses that drain. Musculoskeletal infections can also cause joint pain, stiffness, and swelling, while infections in the lymph nodes usually cause enlarged lymph nodes (lymphadenitis). Disseminated NTM can cause scattered skin lesions and other symptoms.

## YOUR TREATMENT: THE EMPHASIS IS ON YOU!

Living with a mycobacterial infection requires a skilled and experienced medical team to design and implement a treatment protocol. The success of your treatment relies on YOU, your medical professionals, and your medicines.

Fortunately, you can play an active role in the progress of your treatment. It is important to be committed to wellness and seek the support of family and friends. Your lifestyle and routines may have to change. The changes you make are to improve your health and lengthen your life, and with a positive attitude these can be rewarding rather than burdensome.

Once you have fully discussed your condition and treatment plan with your doctor, you have the responsibility to implement your treatment and follow through with full commitment.

**1. Taking Medicines** – Multiple medications are routinely prescribed. It is imperative to take medications as prescribed. *Do not stop taking medications when you begin to feel better.* The doctor will instruct you when it is safe to stop your medications.

Your medications may cause side effects. Call your doctor if you develop ANY side effects. Some of the antibiotics used to treat NTM infections may also interact with medicines you might be taking for other conditions, so it's important that you give your doctor an accurate list of everything you're taking (including supplements) and always check with your NTM provider before starting any new medications.

The American Thoracic Society (ATS) and Infectious Disease Society of America (IDSA), and the British Thoracic Society (BTS) recommend a standard treatment for pulmonary NTM disease consisting of three or four medications. The ATS/IDSA statement also contains recommendations for standard regimens of antibiotic treatment for extrapulmonary NTM.

Specific combinations of antibiotics work better together because they attack the bacteria in multiple ways. Drug combinations are often prescribed to effectively treat a specific strain of NTM. For this reason, it is very important your sputum samples are sent to a qualified, specialized mycobacteriology lab for precise identification of the species and sensitivity testing.

If the standard therapy is ineffective, another combination of medications will be prescribed based on the strain of NTM.

*For more information on antibiotic medications, refer to the chart in this pamphlet or at **ntminfo.org**.*

### 2. Route of Medicines

**A. Oral** – Pills or liquid medications taken by mouth. Make sure you understand what time of day to take medicines and whether they should be taken before, after, or with meals.

If you have difficulty swallowing pills, put your chin to your chest and swallow them. Placing pills in soft food like applesauce is another option. Do not tilt your head back, as this can make it easier for pills to slip into your airway.

**B. Intravenous (IV)** – IV medicines infused via a port or peripherally inserted central catheter (picc) line. The duration of IV administration varies. It is important that you know how to care for any central catheter (port) or picc line to avoid introducing other infections.

**C. Inhaled** – Medications (antibiotics, steroids, or bronchodilators) inhaled directly into your lungs or nose via a nebulizer or metered dose inhaler. It is important to understand how to care for the nebulizer to maintain sterile conditions. Run the unit to clear and dry the tubing after each use.

Extrapulmonary or disseminated NTM may include other treatments, including medications to help with immune function or topical ointments to help keep wound areas sterile or promote healing. Wounds may also need debridement throughout the healing process.

*Visit **ntminfo.org** for more information on all of these treatments.*

**3. Hearing, Vision, EKG and Other Tests** – Some antibiotics may result in hearing or vision loss or affect your heart. Baseline and routine exams are recommended because you might not notice the damage until it has progressed.

**4. Clearing Lungs and Sinuses (Airway Clearance)** – Airway clearance techniques to remove mucus from your lungs are essential. Options include chest physical therapy (chest PT) with postural drainage or use of an airway clearance device (handheld to loosen mucus or a chest wall oscillator or vibrator), possibly including inhaled saline solution. Every time you cough out infected mucus, there is that much less in your lungs to do damage and that much less for the antibiotics to overcome.

Your doctor may have instructed you to do a sinus wash once or twice a day. If so, be sure that you know the correct procedure and how to sterilize the water and equipment. Visit **ntminfo.org** for sinus wash guidelines established by the U.S. Centers for Disease Control.

**5. Hydration** – Fluid is essential to thin mucus secretions which assists mucus clearance from the airways, which in turn helps you clear mucus from your airways. Tepid-to-warm fluids help to thin mucus. Adequate hydration is also beneficial to the kidneys and liver. Consult with your physician about how much fluid you should drink.

**6. Exercise** – Aerobic and weight training exercise can improve oxygenation and breathing. Prior to starting an exercise program, consult with your physician.

## CAREGIVERS & FAMILIES

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The caregiver role is essential as your family member embarks on the NTM patient journey.

Caring for a loved one with a serious illness like an NTM infection can cause great disruptions and challenges in your life. Recognizing feelings of stress and anxiety should not be pushed aside. Knowing as much as possible about NTM and its treatments helps you make decisions together.

Some helpful tips for caregivers:

- Maintain up-to-date flu, pneumonia, RSV, and COVID vaccinations.
- Wash your hands with soap and water for 20 seconds, dry thoroughly, turn off water faucet with paper towel.

- Use hand sanitizer if soap and water are unavailable.
- Avoid close contact with people who have symptoms of illness, including someone who has tested positive for COVID in the last 10 days, even if they have no symptoms.
- Develop a support system for yourself with family and friends.
- Join a support group – it helps to know you're not alone.
- Schedule some time for yourself.

Health care providers are a valuable source of information needed to help with the long-term regimen needed to treat NTM infections. Listen to your instincts and to your loved one as well. Listen and observe for anything out of the ordinary in case it needs to be reported to the doctor.

Online resources for caregivers include the National Alliance for Caregiving ([caregiving.org](http://caregiving.org)) and the Family Caregiver Alliance ([caregiver.org](http://caregiver.org)).

*Links to these and other resources, as well as more information and helpful tips for caregivers and families can be found at **ntminfo.org**.*

TREATMENTS & SIDE EFFECTS\*

Class	Medication Names (Brand Names)	Form	Notes	Common Side Effects
Rifamycin ^	Rifampin (Rifadin®, Rimactane®)	Capsule	Generally used to treat MAC, along with ethambutol plus macrolide.	Red, brown or orange saliva, sweat, tears or feces; diarrhea/upset stomach; fever, chills, flu-like symptoms; flushing; itching; rash; elevated liver enzymes; blood count abnormality
	Rifabutin (Mycobutin®)	Capsule	Rifamycins may permanently stain contact lenses orange. Consider disposable contact lenses.  Can interact with other drugs, especially anti-fungal medications and newer CF drugs.	
Ethambutol	(Myambutol®)	Pill	Patients on ethambutol should have regular vision checks.	Vision changes; numbness, tingling in hands and feet; rash
Macrolide	Clarithromycin (Biaxin®)	Pill	<b>Do not take a macrolide alone (monotherapy) or in combination with a quinolone as the only companion drug for the macrolide to treat MAC. This combination is associated with the emergence of macrolide resistance.</b>  Patients on azithromycin should have an EKG and regular hearing checks.	Irregular heart rhythm; hearing changes; nausea; muscle weakness; kidney problems; metallic taste; diarrhea; abdominal pain; rash
	Azithromycin (Zithromax®)	Pill		

Class	Medication Names (Brand Names)	Form	Notes	Common Side Effects
Aminoglycoside	Amikacin (Amikin®)	Injection, inhaled, IV	Patients on aminoglycosides should have a baseline hearing test before or at start of treatment. Hearing as well as BUN, creatinine, and electrolytes should be monitored at routine intervals while on therapy.	Hearing loss, tinnitus (ringing in the ears); nausea; muscle weakness; rash; poor balance; kidney problems; risk of increased respiratory adverse reactions (inhaled)
	(ARIKAYCE®)+ FDA-approved to treat MAC lung disease	Inhaled		
	Tobramycin (TOBI®)#	Inhaled, IV		
	Streptomycin	Injection, IM		
Fluoroquinolones ("Quinolone")	Ciprofloxacin (Cipro®)	Pill	<b>Do not take a macrolide alone (monotherapy) or in combination with a quinolone as the only companion drug for the macrolide to treat MAC. This combination is associated with the emergence of macrolide resistance.</b>  At-risk patients should check EKG for QTc interval prior to therapy and after treatment has started.	Upset stomach; rash; diarrhea; headache; loss of appetite; EKG abnormality in at-risk patients or in combination with other medications; dizziness; tendon abnormalities; low blood sugar; adverse psychiatric reactions including depression
	Levofloxacin (Levaquin®)	Pill		
	Moxifloxacin (Avelox®)	Pill		



Class	Medication Names (Brand Names)	Form	Notes	Common Side Effects
Cyclines	Minocycline (Minocin®)	Pill		Sun sensitivity; nausea; diarrhea; dizziness; rash; elevated liver enzymes; blood count abnormality; pancreatitis
	Doxycycline (Vibramycin®)	Pill		
	Tigecycline (Tygacil®)	Injection		
	Omadacycline (Nuzyra®)#	Pill, IV		
	Eravacycline (Xerava®)#	Injection		
Cephalosporin (Beta-lactam)	Cefoxitin (Mefoxin®)	IV		Rash; elevated liver enzymes
Penicillin (also Beta-lactam)	Amoxicillin (Augmentin®)	Pill		Nausea; rash; diarrhea
	Ampicillin-sulbactam (Unasyn®)	IV (oral form available outside the US)		
	Piperacillin-tazobactam (Zosyn®)	IV		
Other Beta-lactams	Aztreonam (Azactam®, Cayston®)#	IV, inhaled		Itching; loss of appetite; rash
	Imipenem (Primaxin®)	Injection, IV		
	Meropenem (Merrem®)	Injection, IV		
Sulfonamides	Trimethoprim/Sulfamethoxazole (Bactrim®, Septra®)	Pill, IV, liquid suspension		Itching; loss of appetite; diarrhea; abdominal pain; dry mouth and skin; orange or brown skin discoloration

Class	Medication Names (Brand Names)	Form	Notes	Common Side Effects
Riminophenazine	Clofazimine (Lamprene®)	Pill	Sometimes used for patients when standard therapy has failed.  Requires FDA or Novartis approval for use on a case-by-case basis.	Loss of appetite; diarrhea; abdominal pain; dry mouth and skin; orange or brown skin discoloration
Oxazolidinone	Linezolid (Zyvox®)	Pill		Rash; abnormal blood count; headache; upset stomach; nausea; diarrhea; vomiting; dizziness; numbness in hands and feet; vision changes
	Tedizolid (Syvextro®)	Oral, IV		

^ Rifampin may decrease the blood plasma level of certain medications used to treat HIV, which may result in loss of efficacy or development of antiviral resistance. Rifabutin concentrations may increase when used with certain medications used to treat HIV; dosing levels should be monitored and adjusted accordingly.

+ FDA-approved for treatment of *Mycobacterium avium* complex (MAC) lung disease as part of a combination antibacterial drug regimen for adult patients who have limited or no alternative treatment options.

# Tobramycin, aztreonam, omadacycline, and eravacycline are FDA-approved for the treatment of serious bacterial infections caused by certain susceptible gram-negative or gram-positive microorganisms. Cayston™ and TOBI™ are FDA-approved for use in cystic fibrosis (CF) patients with *Pseudomonas aeruginosa* lung infections.

\* Medications may not be available in every country. Refer to **ntminfo.org** for the latest information on drugs that become approved or are under investigation, and for clinical trial updates. You can also sign up for email updates via the website.

## MANAGING SIDE EFFECTS

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Medications used to treat NTM infections can be difficult to tolerate. Always consult your physician. Some side effects include:

### Weight Loss

You may find it difficult to keep weight on; this can be a side effect of both the disease and the treatment. In addition to proper nutritional intake, there are medications which can induce appetite.

### Fatigue

Fatigue is a common side effect of both the illness and the treatments for it. While there are no medications that can restore your full energy, there are ways to help fight the fatigue. Proper nutrition, good hydration, and exercise can all help. *For more information, visit [ntminfo.org](http://ntminfo.org).*

### Dry Mouth / Unpleasant Taste

Some patients experience dry mouth or an unpleasant taste, particularly with inhaled antibiotics. There are ways to reduce this side effect, such as special mouth rinses for dry mouth. You may also want to try sucking on hard candies like lemon drops or using new flavors and spices in your food to challenge your taste buds.

### Gastrointestinal (GI) Upset

GI symptoms may include bloating, abdominal discomfort, nausea, vomiting or diarrhea, which can lead to extreme dehydration. Upset stomach may be the result of the antibiotics killing good bacteria which normally reside in your gastrointestinal tract. The good bacteria can be replaced by taking a probiotic supplement. For nausea, ginger in some form such as ginger ale or ginger chews may help. If the nausea is severe, your doctor may prescribe an anti-nausea medication.

## Yeast: A Candid Look at Candida

Candidiasis (yeast infection) is the result of an overgrowth of a fungus, *Candida albicans*.

Symptoms of a vaginal yeast infection may include a foul-smelling discharge, painful urination, redness and swelling of surrounding skin, itching, and burning. Oral candidiasis (thrush) appears as whitish, velvety sores in the mouth and on the tongue, with inflamed tissue underneath which may bleed easily. Consult with your physician if you are experiencing any of these symptoms.

### A Note on Probiotics

Probiotics are live bacteria and yeast that improve your gut health. Taking probiotics while you are on antibiotics for NTM may help prevent antibiotic-associated diarrhea and decrease gastrointestinal complaints such as abdominal pain, bloating, cramping, and nausea. Probiotics are found in cultured foods (e.g., kefir, yogurt) and in supplemental forms (e.g., tablets, powders) at most grocery stores and pharmacies.

Take a therapeutic dose daily. Allow at least two hours (more if you can) between an antibiotic dose and a probiotic dose. Otherwise, the antibiotics will kill the live cultures. Many probiotics require refrigeration so read the instructions on the packaging carefully.

*For more information on candida infections, treatment options, probiotics and prebiotics, visit our website at [ntminfo.org](http://ntminfo.org).*

## PULMONARY FUNCTION TESTS (PFTs)

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Pulmonary function tests (PFTs) are a group of tests that measure how well your lungs are functioning. PFTs are usually performed to follow the progression of lung disease.

### Common Pulmonary Function Tests:

**A. Spirometry:** the patient breathes in deeply and exhales as fully and forcibly as possible to assess airflow into and out of your lungs.

**B. Plethysmography:** measures the air volume a lung can hold, using changes of pressure that occur during breathing.

**C. Diffusing capacity:** the patient breathes in a small amount of carbon monoxide and the test measures how much of this gas gets into the blood. This indicates the ability of the lung to allow oxygen into the blood.

**D. Arterial blood gas measurements:** a small amount of blood is extracted from one of the small arteries in the body (usually in the wrist) to analyze the amount of oxygen and carbon dioxide in the blood.

**E. Oximetry:** Measurement of the oxygen level in the blood using a pulse oximeter.

## SURGERY

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The lungs make up a large part of the respiratory system. The right lung is divided into three lobes and the left lung is divided into two lobes.

Surgery may have a role in cases with localized pulmonary infection. Antibiotics are also typically continued. This may increase the chance that infection is eradicated.

To maximize post operative recovery, your physician may prescribe enhanced antibiotic therapy two to three months prior to surgery.

The remaining lung should be relatively free of disease. The calculated pulmonary function after surgery should be in the range of acceptable to relatively normal or reasonable.

## SURGERY FOR EXTRAPULMONARY OR DISSEMINATED MAC OR NTM

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In addition to a multidrug treatment regimen, surgical debridement plays an important role in the treatment of extrapulmonary NTM infections. Earlier intervention is better because “time is tissue” – the longer you wait to treat the infection with all possible options, the more likely it is that the infection will spread further, requiring more extensive surgery to clear infected tissue. If your infection involves a contaminated implant or joint replacement, the implant should be removed as well.

*For more detailed information on surgical treatment of NTM, visit [ntminfo.org](https://ntminfo.org).*

## PREVENTION & REDUCING EXPOSURE

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Preventive measures may help reduce (though not completely eliminate) your exposure to NTM, including:

- Maintain up-to-date flu, pneumonia, RSV, and COVID vaccinations.
- Wash your hands well (for 20 seconds).
- Avoid close contact with people who have symptoms of illness, including someone who has tested positive for COVID in the last 10 days, even if they have no symptoms and wear a mask if needed.
- Ventilate bathrooms or other shower/steam areas.
- Clean showerheads and kitchen faucet sprayers regularly to remove the biofilm. Then soak in vinegar to remove calcium buildup.
- Use an approved water filter to reduce exposure to waterborne pathogens including mycobacteria and to serve as an immediate barrier against gram-negative bacteria, fungi, and parasites.
- If you are taking medications to treat an immune deficiency, take them as prescribed.

- Be sure to change any water filters very regularly.
- Raise the temperature of water heater to 55° C (131° F).
- Use humidifiers with caution. Avoid ultrasonic humidifiers if possible and clean your humidifier's reservoir frequently. Soak it in undiluted bleach for 30 minutes and rinse it thoroughly. Use sterilized water in the humidifier.
- Wear a dust mask to prevent inhalation of dirt particles while working with potting soil or in the garden and wet the soil to reduce the number of particles released into the air.
- Take steps to reduce GERD (gastroesophageal reflux disease), including elevating the head of the bed.
- Do NOT store cleaning supplies in the AC return air closet.

*For more detailed information on these and other measures to reduce exposure, log on to **ntminfo.org**.*

## ALLERGIES

Substances that irritate your lungs may create additional inflammation and result in increased sputum production, making airway clearance more difficult. Be aware of irritants that you sense you may be allergic to. Take care to avoid irritants that cause skin irritation or dermatitis.

Some possible irritants to be aware of are perfumes and colognes, cigarette smoke, pollens from trees, grasses, and flowers, dust, air pollution, and aerosol sprays.

Indoor air quality can play a part in increasing or decreasing lung irritation.

*More information is available at **ntminfo.org**.*

## NTM AND OTHER INFECTIONS

Patients with NTM infections are also vulnerable to other bacterial infections. Some of these infections may be difficult to treat, particularly aspergillus, pseudomonas, or other gram-negative infections.

It is important to have your sputum checked on a regular basis, particularly when your symptoms change. This culture must be requested separately from the test for mycobacteria.

Patients with extrapulmonary NTM may also get other skin infections including staphylococcus aureus. These infections can cause further tissue damage and lead to sepsis, so you should carefully monitor for signs of spreading infection.

## FOLLOW-UP: KEEP CONTROL OF YOUR ILLNESS

Your treatment is a partnership between YOU, your doctor, and your medicine/treatments. Follow-up is your responsibility.

Because treatment of NTM requires multiple medicines, it is important to schedule regular follow-up visits. Schedule the next visit before you leave the doctor's office. Contact your physician when something changes. Don't wait for a future or scheduled visit.

Listen to your body and communicate. Maintain a log of your symptoms, reactions to medicines and changes you observe about your health. This will help your physician treat your illness effectively.

Never feel foolish about discussing any aspect of your illness and calling or seeing your physician. Your observations may be medically significant, so don't keep them to yourself.



## QUESTIONS TO ASK YOUR DOCTOR

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It is helpful to prepare a list of questions prior to your visit. Bring someone with you to your appointment. The following questions were written from a patient's perspective and are not intended as medical advice.

1. What strain(s) of mycobacteria do I have? Where in my body is the infection located?
2. Was drug sensitivity testing performed? If so, what were the results? If not, can and should it be done?
3. What drugs will I be taking? What is the dosing level for each medication? Can and should therapeutic drug levels be checked?
4. When and how do I take my medication?
5. How long do you expect me to be on the medications?
6. What side effects will I be likely to have? Which side effects should be reported immediately? Do you have any suggestions for coping with side effects?
7. Will IV drugs be necessary?
8. Will I also need inhalers?
9. How often will I have:
  - a. Follow-up appointments with you?
  - b. X-rays/CT scans?
  - c. Lab work? What kind?
  - d. Hearing or vision tests? (Try to have hearing and vision tests done before starting your medications so they will have a baseline by which to judge any changes.)
  - e. Sputum or tissue cultures?
10. What other monitoring will I need?
11. Should I use an airway clearance device? How often?
12. Can I still take over-the-counter medicines/vitamins/supplements? (Be sure to tell your doctor about ALL nutritional supplements, herbs, or over-the-counter products that you take. These can interact with your medicines or decrease their effectiveness.)
13. Would I be a candidate for surgery? Why or why not?
14. What if I lose my appetite?
15. What if I feel depressed?
16. Can I exercise? What kind of exercise?
17. What precautions should I take? What activities should I avoid?

Several medications used to treat NTM have side effects that can impact vision, hearing, and organ function. Speak with your physician about what kind of routine monitoring and testing you will need, including lab work, hearing, vision, and EKG tests. Request and keep copies of all your lab work and radiographic imaging (CT scans, blood work, etc.).

For more information on medications and their side effects, see the medication chart in this pamphlet.

## THE ROLE OF REFERRALS

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NTM is frequently misdiagnosed and often not tested for.

Your local pulmonary or infectious disease specialist is usually the first to diagnose an NTM infection. For an online Physician Referral List and links to treatment centers, visit **ntminfo.org**.

Developing a treatment plan is complex. You may wish to ask your doctor about a referral to a center that specializes in the treatment of NTM infections. Because treating this disease is complex, you might want to look for doctors who are willing to work with other medical professionals as part of your “treatment team.” These may include internal medicine specialists, respiratory therapists, dietitians, nutritionists, mental health professionals, and physical therapists.

If you have found something that works for you, that is great! But before you try anything, particularly something that you ingest or inject, please consult your physician. Certain vitamins and minerals (calcium, for example) can interfere with the effectiveness of certain antibiotics, as can certain food products, so it is important that your doctors know what you are taking in case you need to schedule those differently from your prescribed medications. You can also consult with your pharmacist about drug/supplement interactions.

In addition, you should never start or stop any prescribed medication or treatment without consulting your doctor first.

## LIVING WITH NTM

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### Quality of Life Issues

NTM infection is a serious illness that has an impact on your life, and it can have a significant impact on your family’s life as well. You may feel like your relatives and friends do not understand what you are going through. It is difficult for someone who has never faced NTM to grasp what it is like to live with it, particularly when it is a disease they have not heard of before.

You might find that giving them a copy of this pamphlet will help them better understand what you are dealing with. Do not be afraid to express your needs. A serious illness is upsetting and may result in anxiety or depression setting in. Do not ignore this issue –please seek help.

Visit **ntminfo.org** for more information and resources to help patients and caregivers.

### Travel Tips

Travel, particularly by airplane, can be burdensome for NTM patients because of bringing medications for IV or inhalation, or the need for supplemental oxygen or mobility aids. Thankfully, there are ways to make this easier.

The TSA has approved a printable card that you as a traveler can use to notify agents of any conditions or devices that would require special attention. You can download and print this card at **ntminfo.org**. It is important to note that the cards do not exempt a passenger from screening.

You should also get a physician’s note/letter, explaining your medical issues and the medications and devices needed for them.

### Health Insurance

Health insurance is a key issue facing NTM patients, but understanding or choosing your health insurance is not easy. Whether you are on Medicare or have private insurance, it is important to know your obligations and options. It is important to advocate for yourself to ensure the best possible results from your coverage.

Treating NTM lung disease requires multiple medications. It can be a daunting task to keep track of your daily medical regimen. Maintain a log to keep track of when each medicine is to be taken. You can also download and print a medication schedule at **ntminfo.org**.

When your doctor is away, you may speak with a doctor on call who is unfamiliar with your medical history. It is important for you to keep careful records of what medications you take, in what doses, how often, and how they are mixed if compounded. Remember to follow up with your doctor as soon as he or she returns to the office.

There are numerous apps available for use on your smart phones and tablets, and most come equipped with calendar features, which you can use to set reminders for yourself. There are also many different sizes of strip pill boxes which separate your oral medications by day and time of day.

## RESEARCH & CLINICAL TRIALS

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NTM Info & Research (NTMir) has helped accelerate medical research by funding or co-funding numerous studies related to NTM patient vulnerabilities, infection sources and treatments, the prevalence of the disease in the United States, and assisting other organizations and companies in recruiting patients for clinical trials of new medications being developed to treat NTM lung disease and bronchiectasis.

Information about completed and current studies and other research is available on our Clinical Trials page at **ntminfo.org**. To support this research, please contact us at [ntmmail@ntminfo.org](mailto:ntmmail@ntminfo.org) or 305-901-4NTM (4686). You can also donate through our website at **ntminfo.org**.

### NTM Patient Registry

To make the process of patient recruitment for clinical trials easier and faster, NTMir funded the creation of the NTM Patient Registry (as part of the COPD Foundation's existing Bronchiectasis Registry). There are several participating centers nationwide which are enrolling patients in the Registry. For more information on registering as a patient or becoming a Registry site, visit the Research section of our website at **ntminfo.org**.

Dr. Steven Holland, from the National Institutes of Health, authored an article titled "The Importance of Clinical Trials: Hope for the Future." We encourage you to read the full article, and to find current NTM clinical trials, by logging on to **ntminfo.org**. You can also search for clinical trials that are or will be recruiting at [clinicaltrials.gov](https://clinicaltrials.gov).

## PATIENT SUPPORT GROUPS

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Our website has a list of active NTM and Bronchiectasis support groups across the United States as well as in other countries. This includes a dedicated group for extrapulmonary NTM patients and caregivers as well as one for support group leaders.

Not all NTM patients live close to a support group that holds regular in-person meetings, so we also offer support group meetings virtually via Zoom. In addition, we have an online forum (NTM Connect) for all NTM and bronchiectasis patients as well as their loved ones. Registration for this online support group with more than 3,200 members is free, and we do not share your personal information.

If you would like to start a support group, please email us at [ntmmail@ntminfo.org](mailto:ntmmail@ntminfo.org). We will be happy to provide further guidance on starting your new group.

NTMir is always happy to assist new and existing groups by providing copies of this pamphlet, flyers to put in doctors' offices, stickers with contact information to put on copies of pamphlets left in doctors' offices, and a Support Group Leader training manual. We can also assist with scheduling online meetings and technical support running the meetings.

## GLOSSARY OF TERMS

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**Aerosolized** – Dispersed as an aerosol, which is a suspension of tiny particles in gas. Mist and steam are types of aerosols.

**AFB Smear** – Mycobacteria like NTMs are in a group called acid fast bacilli (AFB). The first test will be an AFB smear which looks for the organism in your sputum sample under the microscope. When organisms are seen in the sputum, the next test performed is the culture to determine if it is NTM, which may take several weeks to become positive. Further testing beyond that is required to determine what type of NTM is in your sputum. Therefore, even your initial AFBs must always be done at a highly qualified lab.

**AIDS** – Acquired Immune Deficiency Syndrome, the disease caused by HIV.

**Airway Clearance Device** – A device which helps loosen and clear mucus from lungs, working by means of vibration of airways, breathing resistance, or other method. For more information on these devices and methods, log on to [ntminfo.org](http://ntminfo.org).

**Alpha-1 Antitrypsin Deficiency** – A genetic disorder caused by defective production of a protein called Alpha-1 antitrypsin, causing decreased activity of the protein in the lungs and a buildup of the protein in the liver, which can cause serious lung or liver damage. Alpha-1 is a known comorbidity of NTM lung infection.

**Aspergillus** – A fungal infection in the lungs.

**Autoimmune Disorder** – A condition which occurs when a patient's immune system mistakenly attacks and destroys his or her own healthy body tissue.

**Autoimmune Pulmonary Alveolar Proteinosis (aPAP)** – A rare lung disease that is caused by an abnormal accumulation of pulmonary surfactant sediment in the alveoli (air sacs), leading to impaired gas exchange (transport of oxygen in and carbon dioxide out) between the lungs and blood.

**Biofilm** – A population of microorganisms (such as bacteria) in which cells stick to each other on the surface. These clumped cells are frequently embedded within a self-produced substance (either polysaccharide or, in the case of nontuberculous

mycobacteria, lipid) which is also referred to as slime. Biofilms may form on living (e.g., lung tissue) or non-living (e.g., household pipes) surfaces and are prevalent in natural, residential, industrial, and hospital settings. They are almost always found inside water pipes.

**Bronchiectasis** (bron-kee-ek'-tas-is) – A condition that results from damage to the airways (bronchial tubes) of the lungs. This damage to the muscle or elastic tissue of the bronchial tubes is called bronchiectasis. For more information, see page 8 or log on to [ntminfo.org](http://ntminfo.org).

**Bronchoscopy** – A flexible tube is passed through the mouth or nose and then down into the lungs in order to view the airways and collect samples from the lungs. Your doctor may use this procedure to collect sputum samples if you are unable to cough up sputum.

**Chest P.T.** – A type of respiratory physical therapy in which the patient receives percussive therapy with cupped hand clapping or with a vibrator to loosen and mobilize secretions, thereby facilitating mucus clearance. This is often performed in conjunction with postural drainage.

**Comorbidity** – The presence of one or more disorders (or diseases) in addition to a primary disease or disorder, or the effect of such additional disorders or diseases on a patient.

**COPD (Chronic Obstructive Pulmonary Disease)** – A generalized designation for diseases involving persistent airway obstruction such as emphysema and chronic bronchitis.

**Cystic Fibrosis** – A genetic chronic lung disease affecting the lungs and digestive system. CF is a significant comorbidity of NTM lung disease. For more information, log on to [ntminfo.org](http://ntminfo.org).

**Debridement** – The medical removal of dead, damaged, or infected tissue to improve the healing potential of the remaining healthy tissue.

**Disseminated** – Extrapulmonary NTM infection which has been identified at more than one site in the body.



**Emphysema** – A form of COPD in which the alveoli or small airways of the lungs are damaged, making breathing more difficult. Emphysema is usually caused by smoking.

**Extrapulmonary** – NTM infection occurring in a part of the body other than the lungs.

**Gram-Negative Infection** – Gram-negative bacteria are a group of germs that can cause respiratory infections. Some NTM patients also get gram-negative lung infections such as *Pseudomonas aeruginosa*, *Helicobacter pylori* (H. Pylori), or *Klebsiella pneumoniae*.

**Hemoptysis (heh-mop-tuh-sis)** – Coughing up blood.

**HIV** – Human Immunodeficiency Virus, the virus which causes AIDS.

**Immune Dysregulation** – An unrestrained or unregulated immune response; an inappropriately robust or weakened immune response.

**Nebulizer** – A device used to administer medication to people in the form of a mist inhaled into the lungs. Be careful to clean the nebulizer carefully to prevent bacteria from being re-inhaled.

**Opportunistic Infection** – An infection caused by pathogens that usually do not cause disease in a host that is not compromised in some way. Perhaps due to bronchiectasis and other factors, some NTM patients later acquire opportunistic infections such as gram-negative infections.

**PCD (Primary Ciliary Dyskinesia)** – An inherited disorder causing defects of motile (moving) cilia. Motile cilia are required to keep the lungs, sinuses, and ears free of organisms and debris that can cause infection and disease. A person with PCD experiences chronic, recurrent infections in the lungs, ears, and sinuses due to the loss of ciliary activity in those areas.

**PICC** – Peripherally inserted central catheter access line for infusion of intravenous (IV) medicines. Usually inserted in the arm.

**Port** – An access line inserted into a vein for the infusion of intravenous (IV) medicines.

**Postural Drainage** – Positioning a patient so that gravity helps clear secretions. The patient is positioned or tilted at an angle usually with head and lungs downward. Chest P.T. may also be done at the same time.

**Probiotic(s)** – Also called “good bacteria” or “helpful bacteria,” probiotics are living microorganisms that are the same as or similar to those found naturally in the human body, particularly the lower gastrointestinal tract, which contains a diverse and complex community of bacteria.

**Pseudomonas (Pseudomonas aeruginosa)** – A gram-negative lung infection that some NTM patients experience.

**Pulmonary Surfactant** – A complex mixture of specific lipids, proteins, and carbohydrates, which is produced in the lungs by type II alveolar epithelial cells. It plays an important role in keeping the lung architecture intact with inflation and deflation of the lungs during breathing.

**Pulse Oximeter** – A medical device that measures the amount of oxygen in your blood. It is put around your finger.

**Sjogren’s disease** – A chronic autoimmune disease in which the immune system attacks the patient’s moisture-producing glands. It can also cause dysfunction of other major organs as well as extreme fatigue and joint pain. The vast majority of those affected are women.

**Sputum/Mucus/Phlegm** – Thick secretions found in lungs, airways, and sinuses that your body produces to help remove dust, bacteria, and other small particles.

**Tinnitus** – Ringing in the ears, which may be caused by taking certain antibiotics. Tinnitus may also sound like high-pitched whining, buzzing, whooshing, or roaring.

**Topical** – A drug product that is administered to the skin or another external body surface such as a mucous membrane.

## ABOUT NTM INFO & RESEARCH



NTM Info & Research (NTMir) is a 501(c)(3) nonprofit organization formed on behalf of patients with pulmonary nontuberculous mycobacterial (NTM) disease for the purpose of patient support, medical education, and research.

Our story begins with Fern Leitman, an NTM patient who co-founded NTMir with her husband Philip. Fern's battle began when she was in her mid-twenties. While living in New York City, she was diagnosed with pulmonary NTM infection and was treated successfully over a two-year period. Twenty years later, Fern became ill a second time with pulmonary NTM disease.

Fern began treatment at National Jewish Health in Denver in 1996 under the care of Dr. Michael Iseman. Throughout her illness, Fern needed more than 26,000 doses of intravenous antibiotics. She was hospitalized more than 30 times and spent an aggregate of more than 14 months in the hospital. Every day, she took at least three antibiotics. Her daily regimen included at least 18 prescriptions, vitamins, and supplement pills to help support her health, three or four inhaled treatments and an IV medication three times a day, as well as two rounds of airway clearance therapy.

Before and during her treatment at National Jewish, Fern met dozens of NTM patients just like her with delayed diagnoses, frightened and often unfamiliar with many aspects of NTM lung disease.

After more than two decades, Fern lost her fight with NTM lung disease. She passed away in October 2014.

Her legacy lives on in NTMir, which evolved from our website, **ntminfo.org**. The website was developed to help NTM patients. A brochure was created based on the content of the site and distributed to pulmonologists and infectious disease specialists in the United States and abroad.

In an unanticipated response, the website generated over 2 million hits during its initial period. People logged on from 22 countries, the United States government,

and major institutions. There was a clear need to develop an organization that could speak for patients and the physicians trying to help them, and from this, NTM Info & Research was launched.

Since its inception, NTMir has funded leading studies. One study confirmed the suspected link between household water and infection. Another showed that NTM is more prevalent than previously thought, has impacted women more than men, and affects older populations more than younger ones. This study further confirms what Fern, Philip and an increasing number of experts already knew - NTM is an emerging infectious disease with devastating consequences.

In addition to funding research, NTMir has successfully lobbied Congress to recognize NTM as a serious disease pathogen. The organization works with the National Institutes of Health and other leading centers of excellence to further study of the disease, has helped form dozens of patient support groups, and helps recruit patients for important clinical trials of new medications. NTMir has worked to secure approval for off-label use of a key drug proven effective against NTM and to ensure that medications vital to NTM treatment are prioritized when in short supply.

### ***What We Do***

- Fund or co-fund NTM research.
- Expand and maintain a large network of online and in-person support groups for patients and caregivers worldwide. To join a support group or to inquire about starting one in your area, email [ntmmail@ntminfo.org](mailto:ntmmail@ntminfo.org).
- Host physician and patient education meetings and webinars across North America and abroad.
- Develop and maintain strong relationships with leading researchers and clinicians.
- Host scientific meetings attended by leading researchers and clinicians.
- Provide an online Physician Referral List so patients can find doctors who know how to treat their NTM lung disease appropriately.

- Assist patients who e-mail and call, providing comfort and guidance so they can improve the success of their treatment.
- Distribute “Insight: A Patient’s Perspective,” the flagship NTM lung disease informational pamphlet, around the world in 11 languages.
- Maintain **ntminfo.org**, the HUB for all things NTM.

### ***Our Accomplishments***

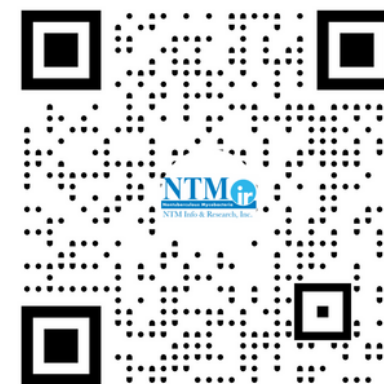
- Established Rapid Information Pilot Studies (RIPS)<sup>™</sup>, funding scientific research that can quickly provide early-stage answers to important questions and provide the base data for major research grant applications.
- Established the NTM Patient Registry to help accelerate clinical trials for new drugs to treat NTM lung disease.
- Teamed with the American Lung Association to jointly fund research.
- Published the first Nutrition Guide for NTM lung disease patients.
- Testified in Congressional Appropriation Hearings on Capitol Hill.
- Secured language amendments for the fiscal 2006 - 2010 budget years directing the National Institutes of Health and the Centers for Disease Control and Prevention to address the concerns of NTM patients.
- Successfully coordinated compassionate use availability for the drug Lamprene/Clofazimine, so patients who have no alternative can receive this life-sustaining medication.
- Worked to ensure that Amikacin, a drug vital to the treatment of NTM lung disease, is prioritized for NTM patients when in short supply.
- Helped ensure a strong patient presence at the FDA’s Patient-Focused Drug Development meeting.
- Worked with industry and other constituents to help bring the first FDA-approved treatment to market for NTM lung disease.

### ***Our Goals***

- Partner with researchers to establish new medical research and multi-center trials.
- Engage new researchers in the NTM lung disease field.
- Partner with industry to find better treatments for NTM lung disease.
- Improve patient outcomes.
- Seek funding to implement these goals.

We hope you have found this pamphlet helpful. Fern started NTM Info & Research to help other patients. Join us to continue helping NTM and Bronchiectasis patients by making a generous donation.

Scan the QR code below or visit **ntminfo.org**.



## ***Ready to learn more?***

Log on to **ntminfo.org** – the HUB for all things NTM!

- Expanded information on treatments, side effects and epidemiology.
- Online forum – a place for patients from all over the world to connect and give each other helpful information and advice.
- Tips from other patients.
- Downloadable versions of our brochure in English as well as 10 other languages including Spanish, Chinese, French, German, Japanese and Korean.
- Listings of clinical trials that are currently recruiting patients.
- News and helpful links to other sites, including **bronchiectasisinfo.org** and **BronchandNTM360social.org**, an online social forum for NTM and bronchiectasis patients.
- Findings of the studies funded by NTMir.
- Ways to get involved and advocate.

**All of this and more is available online.**

### **NTM Info & Research**

14411 South Dixie Highway, Suite 205

Palmetto Bay, FL 33176

305-901-4NTM (4686) x126

ntmmail@ntminfo.org

NTM Info & Research is a 501(c)(3) nonprofit organization.

## **NOTES**

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ALL THE INFORMATION CONTAINED IN THIS PAMPHLET AND MORE  
CAN BE FOUND ONLINE AT **NTMINFO.ORG**

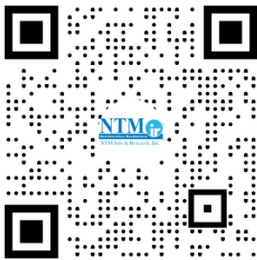


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305-901-4686 | [ntmmail@ntminfo.org](mailto:ntmmail@ntminfo.org) | [ntminfo.org](https://ntminfo.org)

**“NTM lung disease can be very isolating. It’s important to talk about your feelings with people you love and trust so you don’t feel alone. Surround yourself with knowledgeable people who are good listeners. The support and community I have found through NTMir made all the difference.”**

— Joan M., patient

SCAN QR CODE or go to **NTMINFO.ORG**  
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