

“INSIGHT”

A Patient’s Perspective



NTM
Nontuberculous Mycobacteria
NTM Info & Research, Inc.



Learn more at www.ntminfo.org

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TABLE OF CONTENTS

INSIGHT.....	4
WHAT ARE MYCOBACTERIA?.....	4
WHO GETS NTM LUNG DISEASE?	4
HOW DID I GET IT?	5
AM I CONTAGIOUS?	5
WHY HAVEN'T I HEARD OF NTM LUNG DISEASE BEFORE?	6
HOW IS NTM DIAGNOSED?	6
COMMON SYMPTOMS OF NTM.....	7
YOUR TREATMENT: THE EMPHASIS ON YOU!	8
TREATMENTS & SIDE EFFECTS	12
PULMONARY FUNCTION TESTS (PFT).....	15
SURGERY	16
PREVENTION	16
ALLERGIES.....	17
NTM AND OTHER INFECTIONS	18
FOLLOW UP – KEEP CONTROL OF YOUR ILLNESS.....	18
QUESTIONS TO ASK YOUR DOCTOR	19
THE ROLE OF REFERRALS	21
LIVING WITH NTM.....	22
RESEARCH & CLINICAL TRIALS	24
LOCAL PATIENT SUPPORT GROUPS.....	26
GLOSSARY OF TERMS (HIGHLIGHTED IN BLUE)	27
ABOUT NTM INFO & RESEARCH.....	31

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INSIGHT

This pamphlet provides insight into the lung disease caused by nontuberculous mycobacteria (NTM), and empowers the patient to participate in his or her own treatment. NTM is also called atypical tuberculosis (Atypical TB), Mycobacteria other than tuberculosis (MOTT), **MAC** (Mycobacterium avium complex, which is actually one species or type of NTM), environmental mycobacteria (EM) and environmental tuberculosis.

In addition to the information contained in this booklet, you can find much more information and many useful tips on our website, **www.ntminfo.org**.

WHAT ARE MYCOBACTERIA?

Mycobacteria are naturally occurring environmental organisms found widely in both water and soil. They can cause significant respiratory damage, such as **bronchiectasis**. There are **various species of nontuberculous mycobacteria**. Some are readily treated with two or three drugs, while other types are more difficult to treat and are resistant to many drugs. These require treatment that is often more complex and of a longer duration.

WHO GETS NTM LUNG DISEASE?

NTM lung disease (pulmonary NTM disease) is not as well-known or understood as TB. We know that 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 as well as genetic diseases such as **Cystic Fibrosis**, **COPD**, **Alpha-1 antitrypsin deficiency**, and **primary ciliary dyskinesia (PCD)**. However, it is still not completely clear why some people get infected and some don't. Slender Caucasian women are particularly vulnerable to infection, and we now know that immunosuppressive medications such as chemotherapy, prednisone, or drugs used to treat conditions such as rheumatoid arthritis, psoriasis and Crohn's disease, may increase the risk of NTM infection.

In a substantial percentage of cases, patients with NTM have an underlying vulnerability that is either genetic or structural in nature.

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

Though the exact number of pulmonary NTM patients in the United States is not known, some studies estimate it to be as high as 50,000 to 90,000 people in the United States at any given time, with between 12,000 and 18,000 people becoming infected each year.

HOW DID I GET IT?

NTM organisms are everywhere in the environment, including water (both natural sources and treated tap water) and soil. Doctors and scientists believe that some patients become infected with NTM from inhalation of mycobacteria that become **aerosolized** when the patient showers in an enclosed shower stall, uses an indoor pool or sits in an indoor hot tub. For this reason, if you have an underlying condition that might make you susceptible to NTM infection, 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 naturally existing in potting soil, through activities like gardening. Keep in mind that many doctors and scientists believe NTM lung infection is not just due to exposure to the bacteria in the environment but also because of host vulnerability – some people are predisposed to infection while others are not.

AM I CONTAGIOUS?

No. Nontuberculous mycobacteria are not considered to be communicable person to person.

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

You've probably heard of other mycobacterial diseases. The two most famous, or infamous, forms of mycobacteria are different than NTM lung illness. They are *Mycobacterium tuberculosis* (TB) and *Mycobacterium leprae* (leprosy), both of which have caused great human suffering and are contagious (spread from person to person).

Nontuberculous mycobacteria (NTM) should not be confused with TB or leprosy. There is considerable scientific evidence that NTMs are acquired from the environment, not other persons.

HOW IS NTM DIAGNOSED?

Nontuberculous mycobacteria can be difficult to diagnose. Unfortunately, this difficulty sometimes delays initial diagnosis until after the patient has had recurrent infections. This may make treatment more difficult because prior use of single drug therapy may have created some drug resistance. Also, recurrent infections and associated inflammation may have resulted in additional damage to the respiratory system.

The diagnosis of NTM involves the following:

I. Sputum culture – Acid fast bacilli (AFB), which is the basic test to identify mycobacteria. For accurate identification of the strain of NTM and drug sensitivities, testing should be done at a specialized laboratory. These specialized labs can tell your doctor which drugs will work (drug sensitivity) and which ones will not work (drug resistance) on the strain of NTM that you have. Equally important is the need to determine which combination of drugs must be used in order to minimize risk of developing drug resistance, which is a common problem when NTM infections are treated with single drug therapies. If you have trouble coughing up sputum (also called mucus or phlegm), your doctor may decide to perform a bronchoscopy to obtain the needed sample.

II. Chest CT (Computed Tomography) – A CT (CAT) scan is a three-dimensional image generated from a large series of two-dimensional x-ray images taken around a single axis of rotation. Chest x-rays alone provide rudimentary identification of lung ailments. A CT scan provides the doctor with a detailed look at the extent and location of disease and is an important diagnostic tool. It can show mucus-filled airways, which appear as white spots on the images (sometimes referred to as “tree-in-bud” because of their branch-like appearance). NTM diagnosis and follow-up generally requires a high resolution CT scan *without contrast*.

III. Medical History – Knowing what illnesses you have had, including childhood illnesses, may provide your doctor with additional understanding of why certain underlying lung conditions exist. For tips on gathering a family health history, visit www.ntminfo.org.

COMMON SYMPTOMS OF NTM

Patients with NTM infections often experience a variety or even all of the following:

1. Cough – This may be persistent or periodic and may be productive or non-productive, meaning you may or may not cough out sputum. NTM lung disease may cause you to cough up blood (this is called hemoptysis). If you cough up blood, you should contact your doctor. If you are coughing up very large amounts of blood (a cupful or more within a 24-hour period), contact your doctor and seek emergency help immediately. If you are coughing up a small amount of blood (less than several tablespoonfuls within a 24 hour period), call your physician as soon as possible. Any time you cough up blood, it is essential that you remain calm and still to help minimize the amount of blood you cough.

2. Night Sweats, Fever – You may experience some low-grade fever rather than the high and debilitating fever associated with flu or other illness. The sensation of feverishness and sweating is commonly more prominent or only experienced at night.

3. Loss of Weight and Loss of Appetite – It is not uncommon to lose weight, which is why it is important to be aware of weight changes. Please consult with your doctor and/or a nutritionist to determine how to modify and augment your diet so that you get enough calories to maintain your weight at an ideal level that helps your body fight the illness and keep up your strength. Eat, eat, eat. The mycobacteria may compete with your body for calories. You can also find a nutrition guide with suggestions for increasing caloric intake, as well as a printable food diary, at www.ntminfo.org.

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

5. Feeling short of breath

6. Wheezing

7. Chest pain around the lung area

YOUR TREATMENT: THE EMPHASIS 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 doctor, your respiratory therapist, and your medicines.

Fortunately, you have the ability to play an active role in the progress of your treatment. You should be fully 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 – You will likely need to take multiple medications. Take all of your medicines every day for as long as needed. Do not stop when you begin to feel better. The doctor will tell you when the bacteria have been controlled long enough to stop taking your medicines.

Your medications may have some side effects. Call your doctor to discuss any side effects and determine whether your medicines should be changed or the dosage altered. If you are having a severe reaction, call your doctor or pharmacist immediately. Try to tolerate mild side effects. They are less harmful than the long-term effects of uncontrolled NTM infections.

The American Thoracic Society (ATS) and Infectious Disease Society of America (IDSA) recommend a standard treatment for pulmonary NTM disease consisting of three or four FDA-approved drugs. These include Clarithromycin or Azithromycin, Rifampin or Rifabutin and Ethambutol, and Streptomycin or Amikacin. Certain combinations of antibiotics work better together because they attack the bacteria in more than one way.

Occasionally the standard therapy will fail, or another combination of drugs will be recommended depending on the strain of NTM. In these cases, medications may be added or changed.

For more information on these and other medications, please see the “Types of Antibiotics” chart on pages 12 - 14 of this pamphlet. You can also find more information as well as the full ATS/IDSA treatment guidelines at www.ntminfo.org.

You can print out a medication schedule to help you keep track by visiting the Patients section of www.ntminfo.org.

2. Types of Medicines

A. Oral – pills or liquid medicines taken orally (by mouth), usually one or more times daily as directed by your doctor. Make sure you understand what time of day to take the medicines, and whether they should be taken before, after, or with meals.

B. Intravenous (IV) - These types of medicines will be infused via a **port** or “**picc**” line and may be done in a hospital or at home. In some cases, IV treatments are relatively short in nature (a matter of weeks), but in other cases, may be of much longer duration. Be sure you know the frequency with which you are required to take these medicines. It is extremely important that you know how to care for any central catheter (**port**) or **picc** line to avoid introducing any other infections.

C. Inhaled - Some medicines may be inhaled directly into your lungs or into your nose, potentially minimizing side effects or complications. These drugs include antibiotics, anti-inflammatory agents such as steroids, or bronchodilators. It is extremely important that you learn how to care for the **nebulizer** in order to maintain sterile conditions to avoid introducing other bacteria or infections into your lungs. Run the unit to clear and dry the tubing to avoid bacterial growth. Sterilize the **nebulizer** mouthpiece regularly, as directed by your doctor. Certain inhaled medicines may also be taken by metered dose inhalers, which are easier to maintain than **nebulizers**. It is very important that your doctor or respiratory therapist show you the proper way to use these inhalers so that you get the benefit of the full amount of medicine into your lungs or sinuses.

3. Hearing and Vision Testing – Some of the antibiotics your doctor may prescribe can affect your hearing or vision. For example, ethambutol may cause optic nerve damage that can only be detected by an eye exam; by the time you perceive a problem, it may be too late, so regular checkups are recommended. Other antibiotics may damage your hearing initially, in the high-frequency range, so you might not notice the damage until it has progressed.

Ask your doctor about getting baseline tests on your hearing and vision when beginning treatment for NTM lung disease. For your vision, it may be advisable to see a neuro-ophthalmologist because the vision damage may require special training or equipment to detect.

4. Clear Your Lungs and Sinuses (Airway Clearance) - You and your doctor may have selected one or more ways to clear the mucus from your lungs. It could be chest physical therapy (**chest PT**) with **postural drainage**, use of a **flutter valve**, use of a **pep valve** or an inflatable electric vest. The respiratory therapist will likely teach you additional clearance methods including a deep or “huff” cough. Whatever method of mucus clearance you have discussed with your doctor, please remember that 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. Extra mucus can collect in your lungs and make you sick. Your doctor and respiratory therapist will decide which method you should use and will teach you how to do it. 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. The purpose of a sinus wash is to get rid of excess mucus and to prevent this mucus from draining into your lungs. It is extremely important to avoid using contaminated equipment that could introduce some other infection. A respiratory therapist will show you how to do the sinus wash. (Visit www.ntminfo.org for revised sinus wash guidelines established by the Centers for Disease Control.)

5. Drink Copious Amounts of Fluid – Patients with NTM disease need more fluids. Fluid is essential for thinning mucus secretions, which, in turn, helps you clear mucus from your airways. It also helps your kidneys and liver process medications. Try to minimize drinks such as alcohol and coffee, tea or any other drink that acts as a diuretic and actually results in dehydration. Drink juice and water; when possible, combine juice with your water to get extra calories.

6. Exercise – Exercise is important to help maintain and improve endurance overall. Some patients report that the hard breathing associated with exercise helps them clear their lungs. Exercise is a recommended part of most treatment plans but you must discuss the extent and type with your doctor before starting an exercise regimen.

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;
	Rifabutin (Mycobutin)	Capsule	Patients on rifamycins should not wear soft contact lenses as they may permanently stain orange.	flushing; itching; rash; elevated liver enzymes; blood count abnormality
Ethambutol	(Myambutol)	Pill	Patients on ethambutol should have regular vision checks.	Vision changes; numbness, tingling in hands and feet; rash
Macrolide	Clarithromycin (Biaxin)	Pill	Do not take a macrolide alone or with a quinolone as this can cause drug resistance.	Hearing changes, nausea; muscle weakness; kidney problems; metallic taste; diarrhea; abdominal pain; rash
	Azithromycin (Zithromax)	Pill	Patients on Azithromycin should have regular hearing checks.	

CLASS	MEDICATION NAMES (BRAND NAMES)	FORM	NOTES	COMMON SIDE EFFECTS
Aminoglycoside	Amikacin (Amikin)	Injection, inhaled, IV	Patients on aminoglycosides should have regular hearing checks, including a baseline hearing test before or at start of treatment.	Hearing changes, nausea; muscle weakness; rash; poor balance; kidney problems
	Tobramycin (Tobi)	Inhaled, IV		
	Streptomycin	Injection, IV		
Fluoroquinolones ("Quinolone")	Ciprofloxacin (Cipro)	Pill	Do not take alone or only with a macrolide as this can cause drug resistance.	Upset stomach; rash; diarrhea; headache; loss of appetite; EKG abnormality in at-risk patients or in combination with other medications; dizziness; tendon abnormalities
	Levofloxacin (Levaquin)	Pill		
	Moxifloxacin (Avelox)	Pill	At-risk patients should check EKG for QTc interval prior to therapy and after treatment has started.	
Tetracycline	Minocycline (Minocin)	Pill		Sun sensitivity; nausea; diarrhea; dizziness; rash; elevated liver enzymes; blood count abnormality
	Doxycycline (Vibramycin)	Pill		
	Tigecycline (Tygacil)	Injection		
Cephalosporin (Beta-lactam)	Cefoxitin (Mefoxin)	IV		Rash; elevated liver enzymes

PULMONARY FUNCTION TESTS (PFT)

What are they and why do I need them?

Chest x-rays and CT scans show if there are any abnormalities affecting your lungs. Pulmonary function tests (PFTs) indicate how the lungs are functioning; specifically, are your lungs able to bring enough oxygen into the air sacs and allow the oxygen to get into your blood for use by other vital organs?

Pulmonary function tests are usually performed in order to follow the progression of lung disease and are also used to determine if surgery is appropriate. PFTs consist of a battery of measurements, done in facilities called Pulmonary Function Laboratories, and are designed to measure the volumes and flow of air that enters and leaves your lungs, as well as how efficiently the gases are able to pass from the air sacs into the blood.

Some of the most common Pulmonary Function Tests are:

- A. Spirometry:** the patient breathes in deeply and exhales as fully and forcibly as possible, so the measurement of the lungs' ventilatory function can be assessed.
- B. Body plethysmography:** measures the gas volume of the lung, using changes of pressure that occur during breathing.
- C. Diffusing capacity:** the patient breathes in small amounts 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 minute amount of blood is extracted from one of the small arteries in the body (usually in the wrist) in order to analyze the amount of oxygen and carbon dioxide in the blood.
- E. Oxymetry:** also provides a measurement of the oxygen level in the blood using a device (**pulse oximeter**) placed on the patient's finger for a minute or two.

CLASS	MEDICATION NAMES (BRAND NAMES)	FORM	NOTES	COMMON SIDE EFFECTS
Penicillin (also Beta-lactam)	Amoxicillin	Pill		Nausea; rash; diarrhea
	Ampicillin-sulbactam	IV (oral form available outside the US)		
	Piperacillin-tazobactam	IV		
Other Beta-lactams	Aztreonam (Azactam)	IV		Itching; loss of appetite; rash
	Imipenem (Primaxin)	Injection, IV		
	Meropenem (Merrem Trimethoprim)	Injection, IV		
	Sulfamethoxazole (Bactrimo, Septra)	Pill		
Leprostatic	Clofazimine (Lamprene)	Pill	Sometimes used for MAC patients who have failed standard therapy. Requires FDA approval for use on a case-by-case basis.	Loss of appetite; diarrhea; abdominal pain; dry mouth and skin; pink, red, orange or brown skin discoloration
Oxazolidinone	Linezolid (Zyvox)	Pill		Rash; blood count abnormality; headache; upset stomach; numbness in hands and feet; vision changes

SURGERY

Your lungs are made up of three lobes on the right and two lobes on the left, although each lung is about the same size. Sometimes lung damage from an NTM infection may be isolated or most severe in one lobe or one area of your lung. Surgical removal of that lobe or area combined with other treatments may be recommended.

Surgery is a form of treatment that may work in conjunction with antibiotics for some patients with NTM infections. Surgery almost never replaces the need for antibiotics but may eliminate the need for some antibiotics or shortens the length of time others are used. Surgery is sometimes recommended for patients with localized NTM disease such as those with middle lobe or lingula disease. Patients with large or thick-walled lung cavities, and patients with destroyed portions of the lung are candidates for surgery.

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

PREVENTION

Influenza, which is commonly called flu, can be serious for a patient with an NTM infection. Speak with your doctor to be certain you understand the difference between the “flu” and a cold. For patients with chronic lung disease, an annual flu shot or vaccine and a periodic (once every five years) pneumovax or vaccine against pneumonia is generally advisable.

Try to avoid contact with people who have colds or the flu, particularly sharing drinking glasses or utensils.

Wash your hands thoroughly with soap and water frequently, and carry hand sanitizer with you.

Other measures may help reduce your exposure to NTM. These include:

- Properly ventilating bathrooms or other shower/steam areas.
If you have an underlying condition that might make you susceptible to NTM infection, you may wish to speak to your doctor about the advisability of bathing in a tub rather than showering.
- Cleaning your showerheads regularly to remove the **biofilm**, which acts as a breeding ground for mycobacteria, by removing the showerhead and disassembling it to the best of your ability, then scrubbing it with soapy water. After cleaning it, you can also soak it in vinegar to remove calcium buildup.
- Raising the temperature of your household water heater to 55° C (131°F) to kill the mycobacteria in the hot water.
- 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. When filling the humidifier, first boil the water for 10 minutes to kill any NTM. Allow the water to cool slightly before you pour it into the humidifier.

For more information on these and other measures to reduce exposure, log on to our website, www.ntminfo.org.

ALLERGIES

Allergic reactions that irritate your lungs may create additional inflammation and may result in increased **sputum** production, making airway clearance more difficult. Be aware of irritants that you sense you may be allergic to.

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

Indoor air quality can play a part in increasing or decreasing lung irritation. For more information on this, log on to www.ntminfo.org.

NTM AND OTHER INFECTIONS

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

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

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 mycobacteria usually requires multiple medicines, it is very important that you schedule regular follow-up visits with your doctor to monitor your condition. It is best to schedule the next visit at the end of each visit.

Even if your follow-up visits are pre-scheduled, it is your responsibility to contact your doctor when something changes. He or she will be able to decide whether new testing is warranted to determine whether or not your treatment plan should be modified.

If you do your part, the doctor can determine when to have your **sputum** analyzed and when to get an updated CT scan to determine if the course or severity of disease has changed. This is the most important reason for timely and early follow-up. It allows your doctor to work in partnership with you to keep control of your illness.

Listen to your body and communicate. Keeping a log of your symptoms, reactions to various medicines and anything else that you observe about your condition will help your doctor treat your illness effectively.

Never feel foolish about discussing any aspect of your illness and calling or seeing your doctor. Your observations may be medically significant, so don't keep it a secret - let your doctor decide.

QUESTIONS TO ASK YOUR DOCTOR

You can also download and print these questions online at www.ntminfo.org.

These sample questions are meant to be a guideline of the types of questions you may want to ask your doctor. Sometimes it is helpful to have a list so you don't forget. It might help to bring someone with you to your appointment if you are especially anxious. You may want to take a tape recorder with you, but you should first ask your doctor's permission to use it. These 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 lungs is the infection located?
2. Was drug sensitivity 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 the less serious side effects?
7. Will IV drugs be necessary?
8. Will I also need inhalers?
9. What monitoring will I need? (See examples below.)
10. How often will I have:
 - a. Follow up appointments with you?
 - b. X-rays/CT scans?
 - c. Lab work?
 - 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** cultures?

11. Should I use an **acapella**® or **Flutter Valve**® or other 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?

Some examples of the type of monitoring that may be needed – consult your physician: You will probably need regularly scheduled lab work (CBC, CMP) Some side effects are especially common with certain antibiotics and need their own specific tests.

This is only a partial list:

Clarithromycin – hearing and balance as directed by your doctor

Azithromycin – hearing and balance as directed by your doctor

Amikacin – hearing, balance (vestibular) every 2-4 weeks / drug levels and kidney function every 1-2 weeks or as directed by your doctor

Ethambutol – color vision and visual acuity - monthly

Other things to consider:

Request and keep copies of all your lab work. Keep your x-ray/CT scan films yourself, or consider having them done where they can be put on a CD.

THE ROLE OF REFERRALS

NTM is infrequently diagnosed, but is likely not a rare condition. Rather, it is frequently misdiagnosed and often not even tested for.

Your local pulmonary or infectious disease specialist is the first step in diagnosing an NTM infection so that you can be treated. If you need to find a local specialist, NTMir has a Physician Referral List on their website, www.ntminfo.org.

Treatment of an NTM infection can be quite complex and it is best to have a specialized mycobacteriology lab analyze your **sputum** so the species of NTM is accurately identified. This will help your doctor determine the best drug combinations to be used in your treatment.

Because of the complexity of developing a treatment plan, you may wish to ask your doctor about the feasibility of a referral to a center that specializes in treatment of NTM infections. The treatment course developed for you will be a partnership between your local physician, a pivotal member of your care team and the doctors at the referral center.

You can find links to treatment centers and a list of physicians who are experienced in treating NTM lung infections on our website, www.ntminfo.org.

The choice of the patient who authored this booklet was to go to National Jewish Health (NJH) in Denver because they specialize in treatment of respiratory diseases including mycobacterial infections. Her local pulmonary specialist works closely with the doctors and lab at NJH to coordinate ongoing treatment. Often the diagnosis and treatment of NTM lung disease involves more than one physician, and there are other medical disciplines that can further support you as a patient. Because treating this disease is so complex, you might want to look for doctors who are willing to work with other medical professionals as part of your “treatment team.”

In addition to **pulmonary** and **infectious disease** specialists, other medical professionals who may be valuable additions to your team include **internal medicine** specialists, **respiratory therapists**, **dieticians** or **nutritionists**, and **mental health** professionals.

Many patients also like to explore alternative medicine treatments. Although most alternative medicines and treatments are not FDA-approved or scientifically vetted through clinical trials, some patients report therapeutic benefits from different kinds of alternative medicine and vitamins or supplements.

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, for example, can interfere with the effectiveness of certain antibiotics, so it is important that your doctors know what you are taking, in case you need to schedule those treatments differently from your prescribed medications.

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

LIVING WITH NTM

Travel Tips

Travel, particularly by airplane, can become burdensome for NTM patients who deal with medications through IV or inhalation. Thankfully, there are ways to make this much easier for you, your traveling companions and any security personnel you will deal with along the way.

The TSA has approved a wallet-sized 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 from our website, **www.ntminfo.org** (see the Patients section of the site). It is important to note that the cards do not exempt a passenger from screening.

You may also wish to 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 with a private insurance program, it is important to know what your obligations and options are. You will need to advocate for yourself as the patient in order to ensure the best possible results from your coverage.

For more information on what you should know about your health care coverage, log on to **www.ntminfo.org/patients**.

Keep Track of Your Treatment

Because treating NTM lung disease requires multiple medications, it can be a daunting task to keep track of your daily medical regimen. You may wish to develop a medication schedule to help you keep track of when you take your medications and in what dosages. You can also download and print a medication schedule from **www.ntminfo.org/patients**.

You can also use modern technology to help you remember when to take your medications! Most cellular phones and smart phones today 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 out by day, and can also separate them out by time of day as well. These are usually available at your local pharmacies.

NTM Info & Research has helped accelerate medical research by funding or co-funding numerous studies related to NTM patient vulnerabilities, NTM infection sources and treatments, and prevalence of the disease in the United States.

Rapid Information Pilot Studies (RIPS)[™]

NTMir developed the innovative RIPS[™] program to speed up the rate of scientific study, stimulate research interest and provide new understanding about risk and treatment issues for NTM lung disease patients. RIPS[™] provides leadership and guidance on unanswered questions regarding NTM host (patient) vulnerability, sources of infection, and clinical and treatment issues. These pilot studies are conducted to stimulate thinking and research, and to provide a basis for researchers to apply for large-scale funding.

Information about completed and current RIPS[™] studies and other research is available at www.ntminfo.org. RIPS studies have been funded by the NTM patient community. To support this research, please contact us at ntmmail@ntminfo.org or 305.667.6461. You can also make a donation through our website.

NTM Patient Registry

In addition to funding research, NTMir assists with patient recruitment for clinical trials and studies on an ongoing basis. To make this process easier and faster, NTMir funded the creation of the NTM Patient Registry (as part of the COPD Foundation's existing Bronchiectasis Registry). There are 14 participating centers nationwide which are enrolling patients in the Registry. For more information, visit the Research section of our website, www.ntminfo.org.

Dr. Steven Holland, from the National Institutes of Health, authored an article on the importance of clinical trials and research. Parts of the article are excerpted below; to read the full text of the article, log on to www.ntminfo.org.

The Importance of Clinical Trials: Hope for the Future

excerpted from the article by Steven Holland, M.D.

Until recently, the study of NTM was largely derived from what we learned over the years about tuberculosis (TB). This TB information has proven extremely valuable, but somewhat limiting. Once an infection is determined to

be nontuberculous, many medical professionals either lose interest in what to do about it, or lack the knowledge needed to properly treat it. While physicians formerly saw many more cases of TB than NTM, today the situation is reversed. Key questions in NTM research include the areas of epidemiology, environment, growth and survival, virulence, and unique drug targets. These elements are critical to the understanding of who gets infected, how infection occurs, the role of these infections in disease, the ability to identify these infections over time and the ability to treat them.

Applied (or translational) research is performed to answer specific, practical questions. It uses basic scientific information to find ways to improve our approaches to problems. In relation to NTM, applied research aims at resolving or reducing the effects of NTM related health problems through treatments, therapies, medications, etc. The goal is to use basic observations to understand clinical disease. An example would be an attempt to identify drug targets, and then testing those targets with drugs (already available or in development) that might not otherwise be used for NTM infection. In addition, we could conduct research that looks at epidemiological aspects of NTM, and then identify issues of susceptibility (age of onset, gender, specificity, family clustering).

Clinical trials are the foundation on which modern medical recommendations should be based. The only way to accurately and reliably identify, understand and verify medical truth is through a clinical trial. In a clinical trial, one potential therapy is tried out against another. Usually, one therapy is the standard of care, and one is experimental. This type of clinical trial is particularly difficult in a disease like NTM infection, since even the standard of care has never been rigorously demonstrated to be effective. There are different approaches to patients at different treatment centers and even at different times. It is not likely that all treatments are all equally effective, but we are genuinely stymied in determining which approach is the most effective.

The way to achieve truly informative clinical trials, where we learn more about treatments that really work well, is to conduct clinical trials that compare one approach to another. This will give us the opportunity to look at real numbers and data, giving us real answers about how to treat real patients. The most persuasive clinical trials are those that involve multiple centers and patients,

and are randomized (that is, in which the decision about enrollment in a given treatment is left to chance).

These trials help prevent the influence or potential bias in investigators and even patients that could affect the outcome by providing skewed information. Unfortunately, there have not been many prospective trials for NTM infection. While participation in a specific trial will not necessarily make any one patient's life better, it will help the medical field move forward to identify new therapies.

The way that clinical trials are done is absolutely and critically dependent on a partnership between patients, physicians and investigators. Without this partnership being robust, interactive and equal, things will not get better. Together physicians, patients and government can provide leadership, hope and answers.

LOCAL PATIENT SUPPORT GROUPS

On our website, you can find a list of more than 30 active local support groups across the United States as well as in other countries.

Because not all NTM patients live close to a support group that holds regular meetings, we also offer an online forum for all NTM patients as well as their loved ones, physicians and researchers. Registration for this online support group with more than 2,000 members is free, and we do not share your personal information with any third parties.

If there is no local support group in your area and you would like to start one, please email us at ntmmail@ntminfo.org. We will put you in touch with the Support Group Liaison, who can provide further guidance on starting your new group.

NTMir is always happy to assist new and existing groups by providing copies of this Insight patient pamphlet, a tri-fold brochure about our organization, 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 manual.

GLOSSARY OF TERMS

Common Types of Nontuberculous Mycobacteria – MAC or mycobacterium avium complex, *M. kansasii*, *m. abscessus*, *m. chelonae*, *m. intracellulare*, *m. fortuitum*. (*M.* is used as an abbreviation for mycobacterium)

Acapella[®] – A mucus clearance device that works by vibration of airways to loosen mucus. It also increases endobronchial pressure. This device is from Smiths Medical.

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

AFB Culture – Mycobacteria like NTMs are in a group called acid fast bacilli (AFB). One of the ways NTM must be diagnosed is through a culture of your **sputum**. The first culture will be an AFB, to determine if your **sputum** contains mycobacteria of any type. Further testing is required to determine if it is NTM, and further testing beyond that is required to determine what type of NTM is in your **sputum**. Some labs are not sophisticated enough to differentiate between NTMs and TB. Therefore even your initial AFBs must always be done at a highly qualified lab.

Aspergillus – A germ that can cause a fungal infection in the lungs.

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. Alpha-1 antitrypsin deficiency can cause serious lung and/or liver damage. Some NTM patients are diagnosed with Alpha-1 and some Alpha-1 patients develop an NTM lung infection.

Biofilm – A population of microorganisms (such as bacteria) in which cells stick to each other on a surface. These clumped cells are frequently embedded within a self-produced matrix of biofilm extracellular polymeric substance (either polysaccharide, abbreviated EPS 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 surfaces (e.g. household pipes) 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 of the lungs. NTM infection causes your airways (called bronchial tubes) to fill with mucus and over time, may lead to dilation (widening) and scarring of the bronchial tubes. Changes like this that damage muscle or elastic tissue of the bronchial tubes is called bronchiectasis. This bronchiectasis may result in the formation of pouches in the bronchial tubes that can trap mucus. If you are unable to clear the mucus normally because it is trapped in the pouches, the mucus stays in the pouches and this can cause an infection.

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**, chronic bronchitis and **bronchiectasis**.

Cystic Fibrosis – An inherited (genetic) chronic lung disease affecting the lungs and digestive system. It is believed that a defective gene and its protein product cause the body to produce unusually thick, sticky mucus that clogs the lungs and may lead to life-threatening lung infections. This mucus also obstructs the pancreas and stops natural enzymes from helping the body break down and absorb food. There is significant overlap between CF and NTM patients. Although usually diagnosed in early childhood, some NTM patients now are being diagnosed with a form of CF as adults.

Emphysema – A chronic obstructive pulmonary disease (COPD) in which the alveoli or small airways of the lungs are damaged, making breathing more difficult. Emphysema is usually caused by smoking.

Flutter Valve® – A mucus clearance device that works by vibration of airways to loosen mucus. It also increases endobronchial pressure. This device is from Axcan Scandipharm.

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**.

Hemoptysis – Coughing up blood.

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 like **aspergillus**, **pseudomonas** and pneumonia.

PCD (primary ciliary dyskinesia) – An inherited disorder of motile (moving) cilia. PCD is also sometimes referred to as Kartagener syndrome (PCD with situs inversus) or immotile cilia syndrome. 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.

PEP Valve – The Pari Pep™ device is an expiratory resistance device that helps patients inflate their lungs. The much longer resistance improves mucus (secretion) clearance. The Pari Pep™ device has adjustable resistance settings.

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

Pseudomonas – A gram-negative lung infection that some NTM patients experience.

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

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 (including ethambutol, Amikacin™, clarithromycin/Biaxin™, and azithromycin/Zithromax™). Tinnitus may also sound like high-pitched whining, buzzing, whooshing, or roaring.

ABOUT NTM INFO & RESEARCH

NTM Info & Research (NTMir) is a 501(c)(3) non-profit 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 with NTM infection 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, CO in 1996 under the care of Dr. Michael Iseman. Over the last 16 years, Fern has needed more than 16,000 doses of intravenous antibiotics. She has been hospitalized more than 30 times and has spent an aggregate of more than a year in hospital. Every day, she takes four antibiotics (five if her condition is worse). Her daily regimen includes 13 prescription pills, six vitamin and supplement pills to help support her health, three or four inhaled medications depending on the course of treatment, and an IV medication three times a day, as well as two rounds of airway clearance therapy.

Fern's story is by no means unique. 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.

She and Philip co-founded a not-for-profit organization, NTM Info & Research (NTMir), which evolved from our website, www.ntminfo.org. The website was developed to help those and other patients. Based on the content of the website, they also created a brochure which was 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, affects more women 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 the disease, and have helped form more than 35 patient support groups in North America. 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 NTM research through its RIPS™ program and through joint funding programs with the American Lung Association.
- Host patient education meetings across North America.
- Develop and maintain strong relationships with leading researchers and clinicians.
- Host major scientific meetings attended by leading researchers & 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.
- Provide encouragement and guidance to support groups across North America.
- Distribute “Insight: A Patient’s Perspective,” the seminal NTM lung disease informational pamphlet, across the world in five languages.
- Maintain the foremost informational website on NTM lung disease as a gateway to support, patient education in five languages, and the newest information regarding NTM data and treatments for medical professionals’ use.

Our Accomplishments

- Established Rapid Information Pilot Studies (RIPS)™, NTMir’s grants program 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 [link] for NTM lung disease patients.
- Established an online Physician Referral List.
- 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.
- Recruited a Board of Directors comprised of nationally recognized physicians, researchers and patient representatives.

Our Goals

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

We hope that you have found this pamphlet helpful. Donations to NTMir cover the cost of printing this booklet so it can be distributed free of charge.

If you would like to support our work, you can donate online at www.ntminfo.org. You can also donate by phone or by mail at the address and phone number listed below. Your gift will help us fund further research through Rapid Information Pilot Studies (RIPS)[™] and other urgently needed research, as well as science and patient conferences.

NTM Info & Research

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

www.ntminfo.org

Ready to learn more?

Log on to www.ntminfo.org!

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

All this and more is available online.

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All the information contained in the pamphlet and more can be found online at
www.ntminfo.org