

## **acapella®/Aerobika®**

A mucus clearance device that works by vibration or airways to loosen mucus.

## **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.

## **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 NTM lung infection.

## **Aspergillus**

A germ that can cause 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.

## **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 (bronchial tubes) of the lungs. NTM infection causes your airways to fill with mucus and, over time, it may lead to their dilation (widening) and scarring. Changes like this that damage muscle or elastic tissue of the bronchial tubes is called bronchiectasis. This 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. 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 are now 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.

## **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.

## **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.

## **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 into 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 the 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**

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.

## **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 sound like high-pitched whining, buzzing, whooshing or roaring.

# Common Medications

Class	Medication Name (Brand Name)	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 as an alternative	
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	Irregular heart rhythm; hearing changes; nausea; muscle weakness; kidney problems; metallic taste; diarrhea; abdominal pain; rash
	Azithromycin (Zithromax)	Pill	Patients on Azithromycin should have an EKG and regular hearing checks	
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  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
	Levofloxacin (Levaquin)	Pill		
	Moxifloxacin (Avelox)	Pill		
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
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 when standard therapy has failed  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