

“Cough, Cough”

NTMir’s Newsletter

Did You Know?

NTMir is on **Facebook** and **YouTube**—check it out!

An article on NTM disease was recently published in **Breathing** magazine. You can read it at www.ntminfo.org.

NTMir’s pamphlet is available online in **French** and **Japanese** as well as Chinese and Spanish.

New Research: Joint Funding Opportunities with ALA and ATS

NTM Info & Research has made formal agreements with two important organizations to fund joint research projects over the next few years.

The **American Lung Association** will fund half of a three year, \$180,000 grant for pulmonary NTM research beginning in 2009. NTMir and ALA will be jointly responsible for the project.

The **American Thoracic Society** (ATS) will fund half of a two year \$100,000 grant for pulmonary NTM research beginning in 2009. Both NTMir and ATS will be responsible for providing \$50,000 to the approved project.

NTMir’s joint research ventures with ALA and ATS are in addition to the **Rapid Information Pilot Studies (RIPS)**TM program, for which NTMir’s leadership hopes to fund at least two projects per year. The size and number of projects will depend on our success in raising funds.

“Acquiring research partners is a major step forward for NTMir,” said Philip Leitman, President of NTMir. “Not only do our partnerships demonstrate a growing awareness and concern about pulmonary NTM in the medical community, but they also make it easier for NTMir to acquire others kinds of research funding in the future.”

Summary: NTM Conference in Toronto, Canada



In May, NTMir worked with Toronto Support Group Leader, Esther Steinberg, to hold a patient and physician conference on NTM in conjunction with the American Thoracic Society’s annual International Conference in Toronto. The conference attracts 15,000 pulmonary physicians from around the world each year.

The NTM conference was a huge success—people were spilling into the aisles of the 100-seat auditorium at Toronto Western Hospital to hear the physician speakers.

Dr. Theodore Marras from University of Toronto spoke about the epidemiology of NTM in Canada.

Dr. Frances Jamieson from Ontario Public Health Laboratories spoke about the importance collecting sputum samples properly and the best way to test for NTM.

Dr. Michael Iseman from National Jewish Health in Denver spoke about clinical diagnosis and management of NTM.

Dr. Marcel Behr from McGill University in Montreal spoke about the genome sequencing project of *M. intracellulare*, partially funded by NTMir, which he is currently working on.

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“Cough, Cough”

What’s in That Supplement?

The recommended treatment protocol for pulmonary NTM disease usually calls for antibiotic therapy, airway clearance and proper nutrition. Yet many NTM patients take or have considered taking over-the-counter vitamins and supplements as a way to improve their recovery and quality of life. NTM patients frequently use acidophilus and similar products to help minimize certain drug side effects.

At a recent National Heart, Lung and Blood Institute (**National Institutes of Health**) conference for public interest organizations, Josephine Briggs, M.D. spoke about supplement use in the United States. Dr. Briggs is Director of the National Center for Complementary and Alternative Medicine. The Center’s mission is to research non-traditional medical practices.

Supplement Use

Women are more likely to use supplements than men, and supplement users tend to be better educated than the average American. Patients with chronic and acute medical conditions turn to supplements and other nontraditional medical treatments in large numbers.

The most commonly used supplement is echinacea, although ginseng, ginkgo biloba and garlic are also commonly used. Some people have tried glucosamine, St. John’s wort, peppermint oil, fish oils, ginger supplements, and soy supplements. The Center provides fact sheets on many supplements at <http://nccam.nih.gov>. NTMir does not endorse or recommend any supplements – please consult your physician.

Manufacturer Ensures Safety

Dietary supplements are regulated differently than food or prescription drugs by the Food and Drug Administration (FDA). **Dietary supplement manufacturers, not the FDA, are responsible for ensuring that their product is safe before selling it.** Manufacturers must be able to provide some evidence that the claims they make about the product are not false or misleading – but the standard is not nearly as rigorous as that for prescription drugs. The FDA actively addresses dietary supplements only when there is a search for a contaminant, such as when the FDA recalled jalapeño peppers suspected to be contaminated with salmonella this July, or when a manufacturer wants to offer a new ingredient not previously on the market.



Supplements often provide very little information about dosage. The FDA does not regulate supplement dosages – this is entirely up to the manufacturer. Dr. Briggs recommends “that patients not exceed the dosage on the label.” Beyond this recommendation, supplement effectiveness and dosage are relatively unknown.

Many supplements also claim that they are “natural.” “There is no good scientific definition of ‘natural,’” said Dr. Briggs. “Opium is your classic natural product, but it is known to be just as hazardous as heroin – so ‘natural’ is no guarantee of safety.”

Talk to Your Doctor

A 2006 survey jointly performed by the

Center and the AARP revealed that more than two-thirds of supplement users over age 50 did not talk to their physicians about their supplement use. More than half of supplement users who did speak with their physicians said that they, not their physicians, had initiated the conversation.

Dr. Briggs pointed out that a physician needs to know all of the supplements a patient takes, and the types of physical activity and treatments a patient undergoes in order to manage the patient’s care effectively. **“The possibility for drug-drug and drug-herbal interactions are, I think, mind-boggling,”** she said. Telling your physician about any supplements you use ensures that your medical care is properly coordinated and safe. This is particularly important for NTM patients who may be taking multiple antibiotics, as well as other prescription drugs.

Tips for speaking with your physician:

- Take charge of your medical care. Bring up supplements when you see your physician – don’t wait for your physician to ask
- When completing a patient history form, be sure to include any treatments or therapies you use that your doctor may not know about
- Before your appointment, make a list of over-the-counter and prescription drugs you take, any supplements you take, and any treatments or therapies you use, such as massage or acupuncture
- Talk to your doctor before you start taking a new supplement, to help determine the safety and efficacy of the supplement

Volume 2, Issue 2**A Message From Philip Leitman, President**

The Virginia Tech Rapid Information Pilot Study (RIPS)[™] NTMir has initiated is a small first step to understanding the role of mycobacteria in the home environment and how that relates to infection. Host (patient) immunity issues and genetic vulnerability are of equal importance. We must discover how mycobacteria and host vulnerability interact for science to provide better outcomes. The report from Dr. Falkinham shows what he is doing with your support. Our new research partnerships with ALA and ATS are built upon the RIPS[™] base, but these are also relatively small steps in the search for better NTM treatments and patient outcomes.

We are all at a critical juncture. I am asking you for help so we can fund more

and bigger research initiatives. Our annual **Friends & Family Holiday Mailer** campaign will begin shortly. Please consider getting involved – you can learn more on the website, or give us a call.

You needn't wait for the Friends & Family campaign, however. NTMir is also close to launching our new website "**Adopt-A-Cause.org**" and an associated campaign, to enable businesses to participate as well. You will be hearing from me shortly about this new endeavor – please make sure you are receiving our emails. If you have not received an email version of this newsletter, please contact us to add your email address to our list.

Thank you each and all for your care, encouragement, input and support.



Philip Leitman,
President of NTMir

Update: Virginia Tech RIPS[™] Water Study**Dr. Joseph Falkinham, III
Virginia Tech**

Research at Virginia Tech, funded by NTMir, is investigating whether one source of pulmonary NTM infection is household water. Currently, 11 of 12 households for which we have completed testing show the water contains the same species of NTM as that in the patient's sputum.

We hope to test a total of approximately 40 homes by the end of the year. Dr. Richard Wallace (University of Texas, Tyler) has

offered to help us perform some state-of-the-art testing at his lab.



This study is just the beginning of an anticipated larger study of NTM in the environment. The next step would be to perform a parallel study of households neighboring those we

have tested to determine whether those neighbor households also have NTM, and in the same numbers.

Such a "matched study" could possibly show whether NTM numbers were higher in households of NTM patients (suggesting number of mycobacteria per exposure was important in causing disease) or equal (suggesting that patient factors [host immunity] or patient behavior were important in causing disease).



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NTMIR PARTICIPACTION 2009

March 2 –3 , 2009

Holiday Inn Capitol (New Location!)

**550 C Street, S.W.
Washington, D.C.**

SAVE THE DATE!

**NTMir will hold its 4th annual education and advocacy
event in Washington, D.C. on March 2-3, 2009 at a new location.**

**Join us for this uplifting and educational event to ensure that our voices are
heard throughout Congress!**