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Free DVD of the 2008 ParticipACTION conference is available NOW (suggested donation is \$18 to cover costs). Please visit www.ntminfo.org to order the DVD.

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NTMIR PARTICIPACTION 2009

March 2 –3 , 2009

Washington, D.C.

SAVE THE DATE!

NTMir will hold its 4th annual education and advocacy event in Washington, D.C. March 2-3, 2009.

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

Please continue to check <http://www.ntminfo.org> for updates and more information about this can't-miss event!

“Cough, Cough”
NTMir’s Newsletter

Did You Know?

NTMir’s website contains a **Physician Referral List** of patient-referred doctors who are familiar with NTM disease.

NTMir’s pamphlet, already available in **Spanish** and **Chinese**, will be available online shortly in **French** and **Japanese**.

NTMir will expand its work in **Canada** with the formation of our **Toronto office** this year.

Update: Virginia Tech RIPS™ Water Study

By Joseph Falkinham, PhD.
Virginia Tech

The Virginia Tech Mycobacteriology Laboratory initiated a project in January 2008 to determine whether household water systems are possible sources of NTM infection. In addition to having collaborating NTM patients collect hot and cold water samples, the laboratory asks that the material on the surface of water taps and showerheads be collected with swabs. Microorganisms, particularly NTM, attach to surfaces and, along with other microorganisms, form what is called a biofilm where they grow.

For the study, sample kits with detailed collection instructions are sent to collaborating NTM patients. The more collaborating patients and household samples received, the stronger the conclusions.

NTM will be isolated from the household water and biofilm samples and, if any of the isolates are the same mycobacterial species of the patient, DNA fingerprints will be compared.

As of April 1st, the Virginia Tech lab has processed 5 of 7 household collections. NTM have been isolated from 4 of 5 (80 %) of the NTM patient households processed to date. The NTM isolates from the 4 patients providing household samples were also obtained. In all 4 cases, the fingerprint of some of the NTM isolates from the households match that of the patient’s isolate.

The data supports the hypothesis that household water systems are a source of NTM infection; however, we will continue to process approximately 20 more household collections.

We at Virginia Tech are grateful for NTMir’s support and the collaboration with patients with NTM disease.

New RIPS™ Study: MAI Genome Sequencing

NTMir has awarded its first international and third Rapid Information Pilot Studies (RIPS)™ grant to Dr. Marcel Behr at McGill University in Montreal, Canada for a study to complete mapping of the genome sequence of the NTM strain called *M. avium intracellulare*, one of the two MAC strains.

“The outstanding reputation of both McGill University and their principal investigator, Dr. Marcel Behr, was a key consideration in awarding this research grant,” said Philip Leitman, Montreal native and President of NMTir.

Dr. Behr will complete the study within 12 months and the sequence will be publicly available on the internet. This information will be used to better understand the bacterium and how to treat the lung infection it causes.

RIPS™ is an innovative program providing guidance about pressing issues regarding NTM host vulnerability, sources of infection, and clinical and treatment issues. Small studies are conducted to provide information within 12 months of grant approval, and will justify large-scale, multi-centered studies to explore the issues identified by the RIPS™ program.

Research Participants Needed for Water Study!
[Visit ntminfo.org](http://www.ntminfo.org)

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“Cough, Cough”

ParticipACTION 2008: Monday, March 3rd

ParticipACTION 2008 was a great success! NTMir's 2008 advocacy and education event occurred in Washington, D.C. March 2-4, 2008.

88 attendees included physicians from leading medical institutions across the U.S. The day was devoted to advocacy and medical training.

Philip Leitman, President of NTMir, warmly welcomed the attendees and provided an inspiring outline of the opportunities and plans NTMir continues to implement.

Paul Billings from the **American Lung Association** gave a brief presentation on how to approach congressional meetings.

John Magnuson from the **National Home Infusion Association** spoke about the

possibility of Medicare-covered home IV antibiotics.

Gary Ewart from the **American Thoracic Society** spoke about the strength of partnerships between organizations such as NTMir and ATS to provide focus and advance efforts for NTM.

Dr. Kenneth Olivier of the **National Institutes of Health** spoke about the genetic links between NTM disease and Cystic Fibrosis, Alpha-1, Marfan's, and PCD.

Dr. John Mitchell from the **University of Colorado** in Denver gave a presentation about surgical management of NTM disease.

John Magnuson from the **National Home Infusion Association** gave a short presentation on the Home Infusion legislation we asked for on Tuesday.

Carrie Gleeksman, M.S. from **National Jewish Medical and Research Center** in Denver, Colorado talked about nutrition for NTM patients.

The day's activities ended with an open question and answer session with Doctors Olivier and Mitchell as well as **Dr. Michael Iseman** and **Dr. Gwen Huitt** (National Jewish), **Dr. Timothy Aksamit** (Mayo Clinic), **Dr. Richard Wallace** (University of Texas, Tyler), **Dr. Anne O'Donnell** (Georgetown University), **Dr. Lisa Saiman** (Columbia University) and **Dr. Matthias Salathe** (University of Miami). The physicians answered many patient questions. It was truly a wonderful opportunity to have so many knowledgeable and caring physicians in one venue!

Control to implement NTM programs.

Rep. Ileana Ros-Lehtinen (R-FL), who has sponsored our language amendments in the House the past several years, committed to doing so again. Similarly, **Senator Jeff Bingaman** (D-NM) committed to sponsoring our language in the Senate and since asked for a \$100,000 earmark for NTM disease.

In past years, our main legislative support was in the House, but this year several Senate offices—including those of Senators **Hillary Clinton**, **John McCain** and **Barak Obama** agreed to support companion language that gives NTMir a far stronger position on behalf of pulmonary NTM patients. Additionally, there was an open and receptive attitude regarding our request for stronger organization within the Centers for Disease

Patients and physicians spread out to attend **63 meetings** at the offices of Senators and Representatives from **29 states**.

Our Congressmen were quite receptive to our cause, and many agreed to actively support our legislative requests. They were moved that NTM patients have been paying for research themselves. We had many more meetings than in 2007 and the meetings were significantly more productive as well.

ParticipACTION 2008: Tuesday, March 4th

Volume 2, Issue 1

A Patient's Story: Jon Bernhard, Buena Vista, Colorado

I live for adventure. Whether climbing uncharted mountains in Alaska, El Capitán in Yosemite, or skiing, “the journey is the destination.”

It all started back in 1985. I had been competing in bicycle races throughout the U.S. In the spring I started having breathing problems, tightness in the chest, limited pulmonary function, etc. For two years I visited every internist, pulmonologist, and asthma doctor west of the Mississippi. Finally, a visiting Infectious Disease doctor at the University of Arizona suggested sending my case for review to National Jewish Medical and Research Center (NJC) in Denver, Colorado.

During Thanksgiving dinner in 1987, Dr. Mike Iseman called to inform me of this rare disease, *Mycobacterium avium intracellulare*. I was one of only 5 diagnoses that whole year. I spent 28 months on a regimen of 6 meds. I lost all fitness and fought for the next 3 years to “get back in the game.” My month-long stay on 2 Goodman at NJC allowed me to research NTM disease and question every NJC staff member in depth

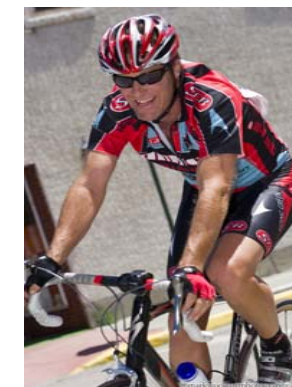
about my condition.

Luckily, I found rock climbing (or it found me). Outlets for misplaced youth let me pace myself back to renewed strength and enjoy being able to breathe. For 11 years I chased dreams and achieved grand heights even with limited lung function.

In 2001 CT scans discovered new infected areas in my lungs. After a 14 month round of meds I turned my attentions away from my own passions of climbing to meeting, working, building a future for all NTM (MAC) patients as best I can. Now after 20+ years I realize I am not alone in this journey. We are one big family trying to make things better for each other. Thanks to the folks of NTMir, I have found an avenue to share and help others.

I still climb, bike, ski, travel, and seek friends everywhere I go. My desire to inspire along with making other NTM patients smile and feel at ease with this disease is all-important to me. Through our patient group efforts in DC and Denver I have found ways to remain passionate about helping others.

make a difference. I want to ensure that patients receive quality information from our organization, coordinate research efforts, and work to educate physicians about diagnosing NTM disease. It is extremely rewarding to work with such an inspiring and dedicated group of people.”



Jon Bernhard,
Patient and
Denver Support
Group Co-Leader

*Jon is a
dynamo!*

Meet Susan Wisliceny

A Brooklyn, New York native, Susan moved to Miami in 1982. Susan and her husband have two daughters. Prior to joining NTMir, Susan worked in a fertility specialist's office for 12 years. Susan joined NTMir in March 2007.

“I feel so privileged to be able to truly



Susan Wisliceny,
Assistant to the
Director