



# 12<sup>th</sup> Annual Conference IUATLD-NAR

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Ms. Fran Du Melle has no financial relationship with companies who have provided support to this meeting that suggests a personal conflict of interest in relations to the planning for the above captioned CME Event.

# From “NCET” to “Stop TB USA”

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**Fran Du Melle, Sr. Director  
International Activities  
American Thoracic Society**

**Convener, Stop TB USA**

**San Diego, CA  
28 February 2008**



# Tuberculosis Then

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- ❑ 1969-1972, TB Project Grant Era
- ❑ August 1981, Program for TB Project Grants authorized, funded in FY 82 supplemental at \$1M
- ❑ 1984, the constant decline in TB rates leveled off and the next year rates began to rise
- ❑ 1989, ACET defined TB elimination as a case rate of less than one case per one million population—the current case rate was 9.3 per 100,000
- ❑ June 1991, ALA/ATS/CDC meeting to discuss challenges to TB control/TB resurgence, concept of NCET identified
  - Failure to sustain domestic TB control
  - Failure to maintain active TB research effort
  - Persistent misperception among the public and policy makers that TB is only a minor problem and found only in minorities and the poor

# The National Coalition for Elimination of Tuberculosis

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- ❑ NCET organized January 1992
- ❑ 58 founding members (83 individuals) from public health, health care, professional medical organizations and Congressional Health committees concerned with the care of individuals with tuberculosis or its control
- ❑ Initial funding from Robert Wood Johnson Foundation through grant to ALA



# The National Coalition for Elimination of Tuberculosis

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## Initial Success:

- Created a venue for Public Private Partnerships to be developed
- Introduced unlikely partners for advocacy
- With funding from RWJ Foundation—supported staff, travel, and meetings including the TB Research Scholar Program which eventually led to the development of the NAR meeting
- Developed new leaders within the TB community
- Benefited from the synergy created by like minds meeting for the first time

# The National Coalition for Elimination of Tuberculosis

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- **June 1997 NCET survey of Membership**
  - **92% of members agreed there was value to continuing NCET**
  - **Original goals reaffirmed with emphasis on advocacy**
  
- **November 2002 NCET Membership Meeting**
  - **Reorganized NCET with new goals aimed at implementing IOM Report recommendations**
  - **Developed new bylaws and governance structure**

# The National Coalition for Elimination of Tuberculosis: Goals

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- To serve as a channel of scientific and public health knowledge for the public and policy makers on the status of tuberculosis elimination globally, nationally and at state and local levels;
- To educate the public and policy makers about the need for sustaining community public health activities for the elimination of tuberculosis, including development of new tools;

# The National Coalition for Elimination of Tuberculosis: Goals

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- ❑ To provide a framework for increasing community participation in the national tuberculosis elimination effort, with emphasis on building awareness in and participation of “at risk” populations;
- ❑ To bring partners together with a clear agreement on the shared objectives for eliminating tuberculosis in the United States; and
- ❑ To stand with our colleagues in the effort to eliminate tuberculosis globally.



# The National Coalition for Elimination of Tuberculosis

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## Membership:

- ❑ Inclusive (not exclusive) membership of individuals and organizations interested in TB care and control
- ❑ Organizational Members or Partners include:
  - U.S., State & Local Gov. agencies (USAID, CDC, HRSA, FBP, Health Departments, Model TB Centers, etc.)
  - Prof. societies and NGOs (ALA, ATS, AAPCHO, NCCHC, etc.)
  - Groups representing TB high risk groups (minorities, foreign-born, migrants, prisoners, homeless, HIV infected, etc.)
  - International (IUATLD, WHO/STOP TB, RESULTS)



# The National Coalition for Elimination of Tuberculosis

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## Membership:

- Individual members include
  - State and “Big City” TB Controllers
  - Health Dept. nurses/laboratorians
  - Representatives and advocates from the research community including public private partnerships and academic institutions
  - Representatives and advocates supporting TB high risk groups
  - Patients/former patients and their families
  - Interested individuals
- No membership fees
- Every member of the Coalition is eligible to participate
- Annual meetings at time of a partner meetings (NAR and NTCA)



# The National Coalition for Elimination of Tuberculosis

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## Governance & Administration:

- Officers
  - Chair and Chair-elect
- Steering Committee
  - Chair, Chair-elect, 10 members from general membership including NCET convener, DTBE Director, and Executive Director (ex officio)
- Convened and administered by ATS
- Mtg. expenses, advocacy, conf. calls, Exec. Dir. administrative/ travel expenses resourced by ATS
- No other resources currently on hand

# The National Coalition for Elimination of Tuberculosis

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## □ Advocacy

- Developed legislation (H.R. 1532/S. 1551, Comprehensive TB Elimination Act; and H.R. 1567 and S. 968, The Stop TB Now Act) to address the IOM recommendations for domestic TB elimination and global TB control activities;
- Developed the *Federal Funding Gap Report* to highlight funding issues in support of annual domestic appropriations for TB control and provided testimony annually by a partner organizations;
- Developed Advocacy Training including two workshops and a training guide, *TB Elimination: An Advocate's Guide*



# The National Coalition for Elimination of Tuberculosis

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## Communications:

- The **NCET WIRE**: Quarterly publication, sent electronically, includes news on funding and leadership issues, Calls to Action, NCET activities, partner issues/activities, new educational products, ATS International Conference TB agenda, and other TB-related meetings.
- Special **NCET WIRE**: A summary of key points from ACET meetings, highlights of latest news on TB-related public health, scientific, and resources issues sent after each ACET meeting.
- Quarterly Updates on TB-related News ***“TB No Longer a Problem?”*** (Note: The ATS Washington Office sends this report to key members of Congress)



# The Road to Stop TB USA

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## August 2007 NCET Leadership/CDC/Advocacy Partners:

- Voted unanimously to transition the NCET Coalition to Stop TB USA
- Retain goals, bylaws and governance structure
- Given requirements in the proposed domestic bill, the Comprehensive TB Elimination Act, initial task was to undertake development of a draft Updated TB Elimination Plan for presentation to ACET:
  - Writing Committee established
  - Launch and Advocacy Committee established



# The Road to Stop TB USA

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## Key Challenges as we launch Stop TB

- Mobilize new partners and ensure an environment in which all partners collaborate to achieve the goal of TB elimination
- Continue to address 3 major areas of concern to reach TB elimination
  - The changing face of TB care and control in the US
  - The challenge of global TB care and control
  - The need for new
- Appropriately resource Stop TB USA to undertake its



# Contact “Stop TB USA”

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