



## 3/14/08 TB WIRE

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**STOP TB USA** was formerly known as the National Coalition for Elimination of Tuberculosis (NCET).

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### **IUATLD North American Annual Meeting & North American Region STOP TB Meeting**

The North American Region STOP TB Meeting was held in San Diego on February 28 where the new **STOP TB USA** coalition was officially launched. Below are points from key speakers at this meeting and the following **STOP TB USA** luncheon. Presentations from all these meetings may be found on the B. C. Lung Association site at: [http://www.bc.lung.ca/lungdiseases/tuberculosis\\_iuatld.html](http://www.bc.lung.ca/lungdiseases/tuberculosis_iuatld.html). Below is a summary of presentations at the STOP TB Meetings.

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### **UPDATE ON PROPOSED TB-RELATED LEGISLATION AND FUNDING**

Nuala S. Moore, Sr. Legislative Representative of the **STOP TB USA** partner the American Thoracic Society, and Mr. John Fawcett, Legislative Director, of the **STOP TB USA** partner RESULTS, both spoke about the current U.S. TB-related legislation and appropriations being considered in Congress.

On the Domestic side, the Comprehensive TB Elimination Act (H.R. 1532/S.1551) calls for increased funding for CDC's National Program for the Elimination of Tuberculosis, for improved outbreak response (provides the CDC with the authority to respond to international outbreaks of XDR-TB), for expanded CDC research on new drugs, diagnostics & vaccines, and for studies of populations at risk of TB. The House bill authorizes \$528 million for CDC's TB program and the Senate bill authorizes \$300 million. New tools/research are included at \$100 million in both bills. The House bill is sponsored by Reps. Green (D-TX), Wilson (R-NM) & Baldwin (D-WI). This domestic bill now has 44 bipartisan cosponsors. The House bill has been referred to Energy & Commerce Committee, chaired by Rep. Dingell (D-MI) & Health subcommittee, chaired by Rep. Pallone (D-NJ). The Senate bill is sponsored by Sen. Brown (D-OH), Hutchison (R-TX) & Kennedy (D-MA) and has 15 bipartisan cosponsors. The Senate bill was passed out of the Health, Education, Labor & Pensions Committee on 11/14/07 and we can expect a Senate floor vote within the next few weeks.

On the Global side, the Global Stop TB Now Act, H.R. 1567/S. 968 has been sponsored in the House by Reps. Engel (D-NY), Wilson (R-NM), and Smith (D-WA). In the Senate, the bill is sponsored by Sens. Boxer (D-CA) & Smith (R-OR). The bill increases resources for the U.S. Agency for International Development (USAID) and CDC USAID funding to \$450M in FY09 and includes related CDC funding at \$100M in FY09. The bill was passed by the House on 7/31/07 and passed by Senate Foreign Relations Committee on 9/11/07. The House bill has recently been included in the House PEPFAR Bill.

Regarding FY09 domestic appropriations, the FY08 \$140.3 million Administration request for CDC TB funding is down from \$146M to \$139M - a proposed cut of \$624K.

Mr. Fawcett commented on the HIV/AIDS, Tuberculosis and Malaria Reauthorization Act, which prioritizes the strategy outlined in the Global Plan to Stop TB, authorizes \$4 billion over five years (FY09-FY13) for bilateral TB programs, strengthens coordination with global AIDS efforts to address TB-HIV co-infection, authorizes U.S. assistance for TB vaccine research, and reauthorizes assistance to the Global Fund to Fight AIDS, TB and Malaria

Mr. Fawcett told attendees three very important lessons for advocacy that he did not learn in Civics Class: (1) news stories are placed (and anybody can do it); (2) congressional staff are not experts (and they need you); and (3)

majorities don't create change (champions do). Coalition members need to remember this as we strive to educate the public and policy makers. He noted that the National TB Controllers Association, the American Thoracic Society, and RESULTS are all here as partners to help in these efforts. He said that our Congressmen listen to their staff, their colleagues, the media, and experts like those working in TB programs - so they need to hear from them (us) about the need for passing and funding of the Comprehensive TB Elimination Act, the Stop TB Now Act, and (reauthorization) of the Global HIV/AIDS, TB and Malaria Act of 2000. Take Action alerts are posted on the RESULTS website at: <http://capwiz.com/results/home/>

Ms. Moore said it is important for TB supporters to ask their House Representative to cosponsor H.R. 1532 & support House PEPFAR bill – US Global Leadership on HIV/AIDS, TB & Malaria Act, to ask their 2 Senators to cosponsor S. 1551 and this can be done by calling or writing or sending a letter or e-mail – or one can use the ATS website at: <http://www.thoracic.org/sections/about-ats/advocacy/take-action-now.html> Or for questions or further information, contact Nuala Moore at: [Nmoore@thoracic.org](mailto:Nmoore@thoracic.org)

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### **FROM NCET TO STOP TB USA**

Fran Du Melle, Sr. Director of International Activities for the American Thoracic Society and a Convener for **STOP TB USA** reviewed the history of the coalition starting with a June 1991 ALA/ATS/CDC meeting to discuss challenges to TB control and the TB resurgence. The concept of NCET was identified in the face of increasing TB morbidity, outbreaks of MDR TB, failure to sustain domestic TB control, failure to maintain active TB research effort, and the persistent misperception among the public and policy makers that TB is only a minor problem and found only in minorities and the poor. NCET was officially organized in January, 1992, with 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 and its control. There was initial funding from Robert Wood Johnson Foundation through a grant to ALA and initial successes included creation of a venue for Public Private Partnerships, new and unlikely partners for advocacy, and the development of new leaders within the TB community.

In November 2002 at the NCET Membership Meeting, NCET was reorganized with new goals aimed at implementing IOM Report recommendations. New bylaws and governance structure were introduced. NCET Goals were established and included serving as a channel of scientific and public health knowledge for the public and policy makers about the need to sustain public health TB activities for the elimination of tuberculosis and to pursue the development of new tools. The coalition's organizational members or partners have been expanded to include: U.S., State & Local government agencies (USAID, CDC, HRSA, FBP, health departments, Model TB Centers, etc.), professional societies and NGOs (ALA, ATS, AAPCHO, MCN, NCCHC, etc.), groups representing TB high risk (minorities, foreign-born, migrants, prisoners, homeless, HIV infected, etc.), and international organizations (IUATLD, WHO/STOP TB, RESULTS). The coalition's individual members also include State and "Big City" TB Controllers, health department nurses/laboratorians and other workers, representatives and advocates from the research community including public private partnerships and academic institutions, patients/former patients and their families, and other interested individuals. There are no membership fees and every member of the Coalition is eligible to participate. There are annual meetings at time of partner meetings (NAR and NTCA).

The coalition's governance and administration is now streamlined and simple with 2 officers (a Chair and Chair-elect) and a Steering Committee consisting of the officers and 10 members from general membership including NCET convener, DTBE Director, and Executive Director (ex officio). The coalition is convened and administered by ATS which covers meeting expenses, advocacy, conference. calls and the Executive Director's administrative/travel expenses. There are other resources currently on hand. For instance, the coalition has worked with ATS and RESULTS and other partners in developing legislation described above. The Coalition also developed the *Federal Funding Gap* report to highlight funding issues in support of annual domestic appropriations for TB control and provided testimony annually by partner organizations. In addition the Coalition developed Advocacy Training including two workshops and a training guide, *TB Elimination: An Advocate's Guide* Communications.

As we move from **NCET TO STOP TB USA**, the coalition will continue to send out the **TB WIRE**, a regular electronic publication sent via e-mail to report news on funding and leadership issues, calls to action, NCET activities, partner issues/activities, new educational products, the ATS International Conference TB agenda, and information about other TB-related meetings like this IUATLD session. In addition, special **TB WIRES** summarize

key points from ACET meetings, highlights of latest news on TB-related public health, scientific, and resources issues. The coalition also sends out Quarterly Updates on TB-related News “*TB No Longer a Problem?*” (Note: The ATS Washington Office sends this report to key members of Congress.)

**STOP TB USA** will continue as an inclusive (not exclusive) membership of individuals and organizations interested in TB care. Our key Challenges as we launch **STOP TB USA** will be to: (1) mobilize new partners and ensure an environment in which all partners collaborate to achieve the goal of TB elimination; (2) continue to address the 3 major areas of concern to reach TB elimination (a) the changing face of TB care and control in the US, (b) the challenge of global TB care and control, (c) the need for new tools; and (3) appropriately resource **STOP TB USA** to undertake its challenges.

In August 2007 at a special NCET retreat, a group consisting of NCET Leadership together with CDC advisors and Advocacy Partners voted unanimously to transition the NCET Coalition to **STOP TB USA** while at the same time retaining NCET’s goals, bylaws and governance structure and continue the TB advocacy and communications. Given requirements in the proposed TB domestic bill (the Comprehensive TB Elimination Act), the retreat group told **STOP TB USA** that the next task should be to undertake the drafting of an Updated TB Elimination Plan for presentation to ACET. Subsequently a “Writing” Committee and a “Launch and Advocacy” Committee were established and the plan is being drafted and will be reported on next.

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## REPORTS FROM THE STOP TB USA WORKGROUPS

Dr. Randall Reves, MD, the **STOP TB USA** Chair, reported that the August 2007 Retreat members recommended the formation of 2 workgroups: (1) a Plan Work Group to update the U.S. TB elimination plan and a Launch Work Group to launch the plan. The goal is to develop and present an updated TB elimination plan for the U.S. with specific recommendations for achievement and with support of partners by May 31, 2008. Why do we need an update? Because the U.S. stated goal of 300 reported TB cases/yr (one per million) in 2010 will not be achieved and with the current 3.8% annual decrease, it will take 70 years to do it! There is also the terrible global impact of TB/HIV, drug resistance, and high TB infection rates in our foreign born (19% vs. 1.8% in US born). Use of TB preventive therapy is limited, even in public health clinics. We need new tools to diagnosis, treat and prevent TB. And we have a lack of public and policy maker support for these efforts. The perception that TB is no longer a problem is reflected in decreasing resources and funding across the country. We need this updated plan.

The **STOP TB USA** U.S. TB plan now under development will not be a detailed scientific document or a lengthy reference document for public health use. The charges to the Work Group is are: to review the progress toward meeting the goal of national TB elimination in the United States as recommended by the IOM 2000 report; to identify the barriers to meeting the TB elimination goals; and to provide specific recommendations for actions to achieve the elimination of TB in the United States. The report and plan will be a concise update with a revised timeline for U.S. TB elimination. The new plan will be based on recommendations in prior plans. The updated plan will be reviewed, supported and valued by key partners linked to **STOP TB USA** Partnership. It will be

supplemented with cost estimates for implementing specific recommendations. The TB Elimination Plan Work Group is making progress and expects to develop the plan on time (May 31).

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## LAUNCH OF STOP TB USA

Dr. Wanda Walton, the Communications, Education, and Behavioral Studies Branch, Division of Tuberculosis Elimination is the Chair of the "Launch Workgroup" working on the launch of STOP TB USA. She noted the idea of national STOP TB partnerships is to bring all national stakeholders together to raise awareness for greater engagement and commitment. The nature of these partnerships is country-specific, expressing typical cultural and organizational diversity.

Dr. Walton said the "launch" of the new name will be centered on March 24, World TB Day. A new logo has been developed (at the top of this electronic newsletter). A STOP TB USA Website and Partnership Home Page is being created at: <http://www.stoptb.org/> The Website will include updated information about the coalition and TB, information about getting involved and how to join, information about World TB Day, a partners' directory, links to partner websites and TB resources, and the TB WIRE E-newsletter. Dr. Walton specifically recommended the guide, *Forging Partnerships to Eliminate Tuberculosis*, that provides TB program staff with information on developing and sustaining partnerships. The guide is available in PDF format. Dr. Walton closed with a quote from Mohandas Gandhi: "You must be the change you wish to see in the world."

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## THE GLOBAL STOP TB PARTNERSHIP

Dr. Marcos Espinal, Secretariat, STOP TB Partnership, WHO addressed the global TB estimates for 2006: 1.7 and 9.2 million new cases. The greatest number of these cases occurred in Asia while the greatest rates per capita were in Africa. There were 490,000 cases of MDR TB worldwide with a related 116,000 deaths. There were 27,000 cases of Extensively Drug-resistant TB (XDR-TB) with 16,000 related deaths. And there were 790,000 HIV-associated TB cases with 200,000 related deaths. R. Espinal pointed out that incidence rates by continent are either stable or very, very slowly falling.

Dr. Espinal said the Global STOP TB Partnership is a worldwide social movement. The partnership's vision is "A TB-Free World." The mission is "To ensure that every TB patient has access to effective diagnosis, treatment and cure, to stop transmission of TB, to reduce the inequitable social and economic toll of TB, and to develop and implement new preventive, diagnostic and therapeutic tools and strategies to stop TB. The targets are to halt incidence growth, half the prevalence/mortality by 2015, and reduce TB incidence to less than 1 case per million population by 2050. The "Global Plan 2006 to 2015" presents a 10 year perspective on the road to the 2050 long term goal. The plan is a response to country needs for long-term planning and it addresses the financial requirements for sustainability. To achieve the 2015 targets, the plan calls for treatment of: 50 million people with TB; 3 million TB/HIV co-infected patients placed on ARV; and treatment of ~ 1 million with MDR. The plan calls for saving 14 million lives from 2006-2015, the introduction of the first new TB drug introduced by 2010, new "point of care" diagnostics introduced by 2010, and development of a new vaccine by 2015.

Dr. Espinal said the Global Stop TB Partnership clearly is adding value and has contributed significantly to the efforts to stop tuberculosis in 2001-2006. Because of the

Partnership's contributions, the progress in global tuberculosis control and research over this period has been much greater than it would have been without the partnership. He said a Global Fund analysis of Performance-Based Funding for Health reported that "The (STOP TB) Partnership has contributed significantly to the efforts to stop tuberculosis ...because of the Partnership's contributions, the progress in global tuberculosis control and research over this period has been greater than it would have been without the partnership".... Value is being added in 5 key areas: (1) expanding and strengthening the coalition; (2) broadening the agenda for TB control and research; (3) expanding the reach, and increasing the strength of global advocacy; (4) coordinating and supporting partner activities in key areas including technical assistance to countries; and (5) improving TB control in both industrialized and low income countries.

Dr. Espinal said we need everyone at the table in our global STOP TB partnerships – the affected communities, the private sector, NGOs, faith based organizations, technical agencies, foundations, government, and academia. Specifically in North America, he said we need the STOP TB partnerships to gain consensus domestically for advocacy and social mobilization and resource mobilization. He noted there are many successful STOP TB coalitions worldwide like: Stop TB Peru where several constituencies funded by CARE are working closely with the government; Stop TB Uganda where 3 NGOs are leading TB control in previously inaccessible areas; and Stop TB Brazil where there is a strong civil society and activism working closely with the government in TB control.

Dr. Espinal concluded by challenging by the attendees saying “We have a global strategy, a global plan, and a global we partnership...Together, let us Stop TB!”

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**STOP TB CANADA – HALTE A LA TBERCULOSE CANADA**

The next speaker was Dr. Anne Fanning, Professor Emeritus, Faculty of Medicine and Dentistry, University of Alberta, and a recognized leader in global TB control efforts. She said the idea for Canada’s STOP TB CANADA or HALTE A LA TBERCULOSE CANADA came from a discussion she had a few years ago in Florence at the “World Lung Congress 2000” when fellow Canadian and IUATLD’s Dr. Don Enarson asked her “What are you doing about Canada’s commitment to the G8?” Out of that conversation came STOP TB Canada and it was officially launched in February, 2001. Members included traditional the TB controllers, the Canadian Lung Association and the IUATLD plus new partners including RESULTS, academics, professional associations, infectious disease specialists, the Thoracic Society, Canadian nursing, the Interagency Coalition on Aids and

Development (ICAD), and NGOs. The stated mission is: to support the Government of Canada in reaching G-8 goal of reducing TB by 50% by 2010 through education, co-ordination, communication and advocacy, updated to 2015. STOP TB CANADA has its own website, a Coordinating board, monthly conference calls, an annual World TB day celebration, and supports efforts to respond to emergencies. Current STOP TB Canada projects include: an Opera fund raiser March 22, 2008 (La Traviata), a Patient Survivor handbook, and an initiative among the Canadian indigenous population.

Dr. Fanning noted that since 2000, about 20 National TB partnerships have been formed around the globe. She said the role for national STOP TB partnerships varies by country. In industrialized countries, the partnerships work on raising donor contributions and carry on efforts to support local TB control. In low income countries, the partnerships work to support and strengthen National TB programs and health infrastructure and to increase country funds and human resources. Both the low income and industrialized countries need to work on advocacy (making noise with decision makers), communication and raising TB awareness, social mobilization, and community involvement. In the end, the goal is to find and cure cases at country level and cure them all! She said our STOP TB coalitions in the industrialized countries are committed and in solidarity with the STOP TB Groups across the world. We are all committed to providing TB care and prevention for all mankind!

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### STOP-TB MEXICO

Dr. Martín Castellanos Joya, of the Mexican National TB Program, spoke next about STOP TB Mexico. He pointed out that advocacy is now acknowledged as an essential element in the integration of multidisciplinary alliances and aimed at improving actions towards the accomplishment of National Tuberculosis Program goals by focusing attention on vulnerable communities. He said that governments alone cannot solve the problems posed by the disease and thus the need to orient the paradigm from a medical model to an integral social approach.

STOP TB Mexico became official in 2004 with a coalition that included a structure of 50 public, private and civil society organizations and institutions, plus health institutions, schools and academies, Associations and Societies, international organizations, the pharmaceutical industry, civil society organizations, the National and State Health Commission, and other institutions. The National STOP TB Committee meets once or twice a year to review progress, challenges and improvement proposals as well as to plan and develop projects for working groups. There are six key working subcommittees: Clinical, TB/HIV AIDS, Nurse DOTS Network, Advocacy, Communication and Social Mobilization, Operational research, and Monitoring and Evaluation.

STOP TB Mexico has been successful in enlisting the support of sports leaders and outstanding individuals in the community with charisma and altruist spirit, sensitive to the problem of tuberculosis and its control alternatives. They work to further the fight-against-tuberculosis within the general population through messages and examples of actions aimed at attaining a "Mexico free of tuberculosis". They promote involvement with the communities informing people about basic aspects of TB. Tuberculosis bulletins are placed in mass media. STOP TB MEXICO promotes participation in the "World's TB Day." Successes include the initiation of "TB Mobile laboratories" to bring detection services near difficult-to-access communities. They have also focused on increasing overall detection, TB prevention and reduction of mortality among persons with TB-AIDS. They have introduced treatment innovation through the "BlisterDoTBalObjective" which facilitates the treatment regimen logistics by decreasing regimen's number of tablets and including the 4 main drugs in one tablet. The impact has been to increase cure rates and reduce treatment default. They have worked with the Bi-national TB Health Card Objective which has strengthened the alliance with the U.S. government and helped to guarantee patient referral and treatment continuity on either side of the border. The impact has been to increase cures and reduce treatment defaults. A TB outreach course has educated nursing staff and professional allies with technical skills so as to have an optimal operation of the tuberculosis program and the integration of nursing schools. The impact has been to increase TB knowledge and improve TB program operations. The TB SUPERINSPECTORS initiative has improved alliances with Educational Sector to integrate children who participate by interviewing families at their schools to identify TB risks. The impact has been to increase co-responsibility and TB knowledge. Finally, the "UnidosporellosFoundation" Mobile DOTS initiative has an objective of bringing treatment closer to patients who cannot go to health units, so that risk of treatment default can be reduced and thus cures and follow-up guaranteed. The impact is to increase cure and reduce treatment default. Progress in implementing these initiatives is being measured at national, state and local levels. Since 2001, TB morbidity in Mexico has been reduced by 17% and TB mortality by 20%.

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Please pass this on to others interested in domestic and global TB prevention, control and elimination efforts.

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