

Participants continued

cured on January 29, 2009. Andre now strongly feels the need for universal access to diagnosis and treatment coupled with a responsive health care system for TB patients. As a motivational speaker for TB activism, Andre hopes to inspire change in his native country of Namibia.

Pham Thu Hoa



Ms. Pham Thu Hoa is a 22-year-old Vietnamese student who contracted pulmonary TB twice. She was first diagnosed with TB in 2008 at Hanoi Lung Hospital and transferred to Hai Ba Trung District TB Unit for treatment. Pham

was cured in 2009 but became re-infected and presented with symptoms in 2011. It was not easy dealing with such a traumatizing disease as a young girl, and she felt like she had to climb a mountain during her illness. However, she was determined to overcome those big challenges to invest in her future. In the midst of studying, she had to focus on her TB treatment and getting cured. During this difficult period, she received great support from relatives, friends, and health care workers. Ms. Hoa was worried about having to face stigma and discrimination, but she was pleasantly surprised that this was not the case in the community and in the health care system. By spirit of youth, she let go of her bad feelings of contracting TB twice and is dedicated to sharing her story and educating others on ensuring early diagnosis and completion of treatment. She considers herself a soldier in the fight to stop TB.

Rachel Orduño



Born in the border town of Juarez, in Chihuahua, Mexico, Rachel Orduño moved to El Paso, Texas, in 1971. At the age of 35, she was diagnosed with diabetes. One year later, in 2007, her latent

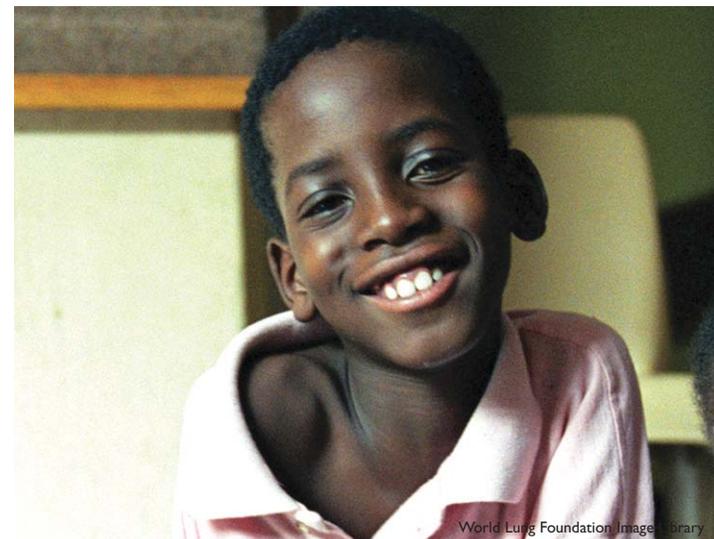
TB infection was activated but attributed to various allergies, upper respiratory infections, pneumonia, and even asthma, and this led to a 3-year delay in receiving a proper diagnosis of TB. Around the same time, her 3-year-old niece was discovered to have TB as well, after a recurring cyst was found to harbor the TB bacillus. Orduño and her niece started daily treatment for active TB disease, while five other family members were placed on preventive therapy. After her TB diagnosis in 2006, she became involved with the Amaya-Lacson TB Photo-voice Project “Border Voices and Images.” Her victory over TB empowered her to raise awareness and fight the spread of TB. A binational, multicultural, and multilingual first-generation Mexican-American, she graduated with a BA in Spanish Literature from the University of Texas at Austin in 1988 and worked with the university’s Recruitment, Retention and Support Services. Rachel has a Teaching Certificate from the Region XIX Alternative Certification Program and a Masters of Social Work from the University of Texas at El Paso.

Rosalie & Faith Stephson



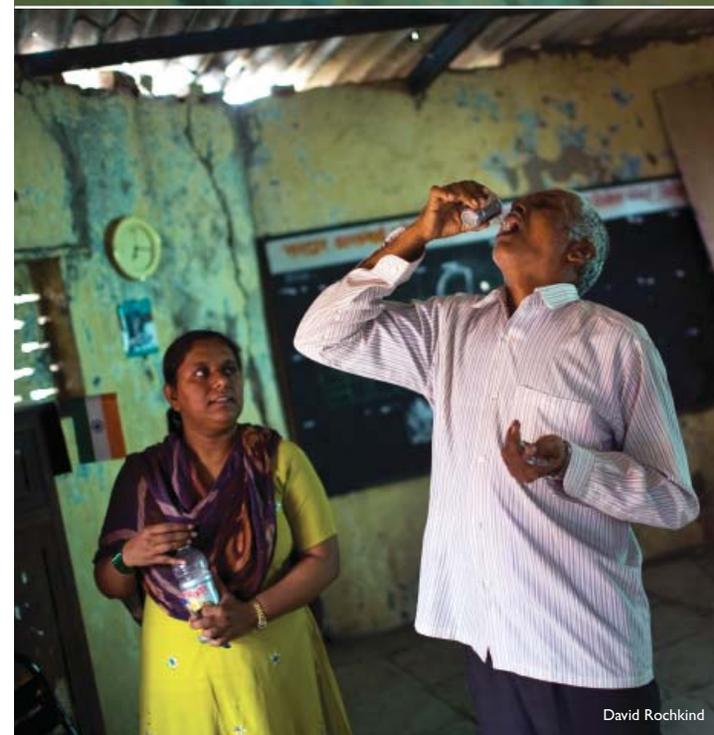
Ms. Stephson, originally from the Philippines, immigrated to the United States in 2005 and resides outside of Houston, Texas. Her daughter (Faith) was first diagnosed with TB at 5 years old and treated in the Philippines. Two years ago, at the age of 12,

Faith developed a swollen lymph node on the neck, and TB was found through a biopsy of the lymph node. This was an unusual complication of her TB. The enlarged lymph nodes near her kidney caused significant hypertension. She had to undergo much more testing than usual. In addition to having to take her TB medications, she had to take high blood pressure medication. In all, she had to take nine pills a day for 9 months. It was a difficult time for her, and she often suffered side effects from the medication most of the time. Happily, Faith’s TB is cured. Her mother, Rosalie, kept Faith’s TB confidential for fear she would be teased or ostracized at school. However, she now feels it is important to tell their story. She hopes that speaking out about Faith’s illness will help raise awareness about TB.



World Lung Foundation Image Library

WORLD TB DAY Voices of TB



David Rochkind

WORLD TB DAY

Voices of TB

Coming together to hear the powerful stories of former TB patients from around the world whose lives have been impacted by this debilitating disease.

March 22, 2012 at 2:00–4:00 p.m.

Holeman Lounge, National Press Club, 13th floor

529 14th St. NW, Washington, DC 20045



David Rochkind

- Moderator -

CURRENTLY based in Washington, DC, David Rochkind is a photographer who focuses on health and crisis issues. After graduating from the University of Michigan with a degree in sociology, David moved to Caracas, Venezuela, where he worked as a freelance photographer, documenting the rise of Hugo Chavez's self-styled "Bolivar-

ian revolution." For the past 3 years, he was based in Mexico working on a book about the long-term costs and consequences of Mexico's drug war. This project, "Heavy Hand, Sunken Spirit: Mexico at War," will be released as a monograph by Dewi Lewis Publishing in October 2012. He is interested in projects that expose normalizing the integration of high drama and conflict into daily life. His passion extends to global health and TB issues. For the past 3 years, David has documented the devastating effects of TB around the world. His reports and photographs from South Africa, India, and Moldova have been published widely in the media. As an advocate, he says, "In order to really understand the disease, and the obstacle it has in treatment and prevention, there really needs to be a more engaging, intense platform to present the work." With support from the Pulitzer Center and the Eli Lilly MDR-TB Partnership, David built the website www.TBEpidemic.org, an educational portal that teaches people about TB and how they can start advocacy campaigns. David hopes it will help students, health centers, and communities learn about TB and how they can advocate for change.

Francis George Apina



Francis George Apina was treated for TB disease in 2004 after all attempts to diagnose TB in him failed because of his HIV-positive status. Francis developed resistance to first-line ARVs

and had a low CD4 count of 7. When he was put on anti-TB treatment, he had multiple opportunistic infections, which took advantage of his low immunity. Based on symptomatic presentation of active TB disease, the doctors decided to put Francis on anti-TB treatment for 8 months – a decision that saved his life. Francis has been on second-line ARV treatment for 7 years now, and his greatest fear is his increased chances of relapsing and contracting drug-resistant TB, multi-drug resistance TB (MDR-TB), and extensively drug-resistant TB. Francis is a TB-HIV advocate and a patient representative at national, regional, and international TB-HIV advocacy organizations and new TB drug research institutions. He is one of the founders of Network Men Living with HIV/AIDS in Kenya (NETMA+), a movement that advocates for constructive male involvement in the fight against HIV and TB in Kenya, where he works as a TB-HIV Programs Manager. As an HIV-TB survivor, Francis is familiar with the challenges associated with the hardships of treatment, the uneven access to medicines, and the problem of stigmatization. Francis believes that education and empowerment should play a bigger role in TB treatment programs. While Francis considers himself lucky, he believes "the fight against TB is one that all patients should win."

Endalkachew Fekadu Demmisse



Endalkachew Fekadu Demmisse was diagnosed with TB in 2004 in Ethiopia. He failed his initial treatment and was finally diagnosed with MDR-TB. Without availability

– PARTICIPANTS –

of second-line drugs or MDR-TB treatment facilities in his country, he managed to receive the needed drugs through the support of an American NGO called Compassion International in Colorado. Those second-line drugs, however, were not without adverse effects, including psychosis, sleep disturbance, constipation, vomiting, and nausea. But after a difficult 2-year treatment course he was cured in 2007. Endalkachew considers himself one of the lucky ones, as three other patients in his treatment group committed suicide, which was thought to be related to the drugs' adverse effects. Since 2007, Endalkachew has dedicated the rest of his life to advocating for TB control. He has organized public health education campaigns, created and published a monthly journal called *Pharmanet*, which promotes rational drug use and treatment adherence. Endalkachew is currently in the process of establishing an MDR-TB association and treatment support group. Endalkachew holds a Bpharm degree in pharmacy and has additional training in communication, web, and graphics. He also published his own book called "The Mystery of God's Will (Amharic)."

Andre Gariseb



Andre Gariseb's ordeal with TB dates back to 2008, when he was 31 years old, in Windhoek, Namibia. At the time, he was working as a freelance radio program producer and presenter at Namibia FM 99, a local commercial

radio station, and at the Ministry of Water and Forestry via Namwater (Namibia's commercial entity supplying water in bulk to the country). In July 2008, he started experiencing very severe diarrhea coupled with heavy coughing, night sweats, and chest pains every time he would cough. After losing 10kg in 3 weeks, he was ultimately diagnosed with TB. Having lost three of his family members to TB, Andre was personally familiar with the stigmatization, the side effects, and the depression that can be associated with the disease. He was