FOR IMMEDIATE RELEASE

Tuberculosis is a human rights issue delegates told at the opening of the 49th Union World Conference on Lung Health in The Hague

Each year nearly a quarter of a million children die an avoidable death from tuberculosis

Wednesday, 24 October 2018, (The Hague, The Netherlands) – The 49th Union World Conference on Lung Health (Union World Conference) taking place in The Hague has opened with a call to treat the global response to Tuberculosis (TB) as a human rights issue.

“That 1.6 million people die each year from tuberculosis (TB) a curable disease, is an affront to basic human rights,” said José Luis Castro, Executive Director of The International Union Against Tuberculosis and Lung Disease (The Union), who are the organisers of the Union World Conference. “There is no more appropriate place than The Hague, the city of social justice, to shout out loud to the world that the unnecessary millions of deaths each year from TB is a global health emergency and requires urgent action.”

Last year 10 million people fell ill with TB and 1.6 million died from the disease. TB, a preventable and curable disease, now kills more people than HIV/AIDS and is the world’s largest infectious disease killer.

The conference theme Declaring Our Rights: Social and Political Solutions highlights the essential need for a human rights approach and greater political commitment to eradicate TB and reduce the global threats of tobacco use, air pollution and other lung diseases. The Union
World Conference is the world’s largest gathering of clinicians, policy makers, public health managers, researchers and advocates working to end the suffering caused by lung disease, with a focus specifically on the challenges faced by low- and middle-income countries. Some 4,000 delegates from over 80 countries are expected to attend.

Her Imperial Highness The Princess Akishino of Japan, and Her Royal Highness Princess Margriet of The Netherlands will both attend the Union World Conference.

HIH Princess Akishino will attend numerous scientific sessions throughout the conference. As Patron of the Japan Anti-Tuberculosis Association (JATA), she will present the prestigious Princess Chichibu Memorial TB Global Award. The award recognises outstanding contributions to global TB control and is presented annually by JATA, a heritage member of The Union.

The royal guests will attend the opening ceremony of the 49th Union World Conference, at which Princess Margriet will speak as patron of the conference’s local hosts, KNCV Tuberculosis Foundation.

“TB is more than a clinical condition,” said Kitty van Weezenbeek, Executive Director of the KNCV Tuberculosis Foundation and the local host of the Union World Conference. “TB thrives where rights do not. People everywhere, no matter who they are, have the right to prevention, treatment and care for TB. We need to accelerate the introduction of new tools and shorter injectable free regimens to reduce suffering and death from drug-resistant forms of TB. The Netherlands has unique expertise and an innovation track record in this field and we will share some exciting developments this coming week.”

Book launch - Childhood TB and Stigma: Conversations of Resilience in the War Against TB

An estimated 239,000 children die every year from TB. Children with TB rarely die when they receive standard treatment for the disease, but 90 percent of children who die from TB worldwide went untreated.

“To think that 650 children die from TB every day, with 80 per cent not even reaching the age of five, is heart wrenching,” said Blessi Kumar, CEO of the Global Coalition of TB Activists (GCTA)
and a Union Board member, launching GCTA´s new book *Childhood TB & Stigma: Conversations of Resilience in the War Against TB* at the official opening press conference.

“Mothers and carers in these stories tell us of how they had to crush the tablets to give their children, or of how getting a diagnosis was a challenge as the children had to have a gastric lavage done, which was painful. It would not be wrong to say we have failed our children who are our future.”

*Childhood TB & Stigma* tells the powerful stories of 13 child TB survivors and their families from countries such as Ukraine, India, Mexico and The United States and the extreme challenges that they went through and eventually overcame.

Nine-year-old South African Angelina is one of the survivors featured in *Child TB & Stigma*. Angelina suffers from a Primary Immune deficiency. She was diagnosed with pulmonary TB when she was two years old.

“We are lucky in South Africa, TB drugs are freely available through public health care systems however it is often not adequately utilized by under resourced communities,” said Janet Grab, Angelina’s mother. “However, stigma can be universal. TB children is different from TB in adults. Angelina didn’t cough at all. When I told the principal of Angelina’s school that she had TB, she was shocked and asked me to not tell anybody about it. She was worried that the other kids would pull out of class and stop attending school.

“Being a healthcare professional myself, I could confidently address her concerns. I got a certificate from Angelina’s doctor and brought the principal material on TB for her to read, and she agreed to let Angelina come to playschool. But my heart goes out to the children and their families in more difficult circumstances who bear the brunt of an enduring stigma every day of their lives.”

The scale of the TB global health emergency was recently acknowledged by the United Nations, which held the inaugural High-Level Meeting on TB in New York last month culminating in a Political Declaration signed by world leaders committed to ending TB by 2030.
The UN Meeting highlighted the need to consider the TB crisis as a human rights issue while it focused on the need to drastically step up investment in research and development that could deliver new diagnostic tools, new drugs and a vaccine.

**Conference Programme**

Across a three–day conference programme, the Union World Conference looks not only at scientific advances, but also at the obstacles to developing safe and user-friendly forms of TB prevention and the delivery of drugs to treat the disease and strategies to address the barriers to making effective prevention and treatment available to all. The global conference features more than 1,000 scientific presentations, including oral and poster abstract sessions, plenaries by the world’s leading lung health experts, symposia, workshops, satellites and a Community Space, De Ontmoeting, open to the general public.

For the first time in the Conference’s history a pre-Conference event **TB Science2018** will be held, focusing on Basic Science.

**Press Programme and Registration**

The Union World Conference press conference programme (full program [here](#)) includes daily overviews of some of the most compelling research being presented at the meeting, including:

- Weds., 24 Oct: Official Opening Press Conference (16:00 – 16:45 CEST)

For journalists who cannot attend in person, **all press conferences will be live-streamed** on [YouTube](#) and available for playback on [The Union’s Facebook Page](#). The conference offers complimentary registration, a fully staffed media centre and extensive professional support.

Details on media registration for the Union World Conference are available [here](#)
Further Information:

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Image bank: https://worldlunghealth.smugmug.com/The-Hague

About the 49th Union World Conference on Lung Health

The Union World Conference on Lung Health, convened by the International Union Against Tuberculosis and Lung Diseases (The Union) is the world’s largest gathering of clinicians and public health workers, health programme managers, policymakers, researchers and advocates working to end the suffering caused by lung disease, with a focus specifically on the challenges faced by low- and lower-middle income populations. Of the 10 million people who die each year from lung diseases, some 80 percent live in these resource-limited settings.

Organising international conferences on TB and related subjects has been a core activity of The Union since its founding in 1920.

About the International Union Against Tuberculosis and Lung Disease (The Union)

The Union was founded in 1920 and is the world's first global health organisation. We are a global leader in ending TB, we fight the tobacco industry, and we solve key problems in treating major diseases. We use science to design the best treatments and policies for the most pressing public health challenges affecting people living in poverty around the world. The Union's members, staff and consultants operate in more than 150 countries and embody our core values of accountability, independence, quality and solidarity.
About KNCV Tuberculosis Foundation

KNCV Tuberculosis Foundation is an international non-profit organization dedicated to the fight against tuberculosis (TB), the deadliest infectious disease in the world. By developing, testing, evaluating and scaling up country specific, patient and community centred TB strategies and interventions we work to impact public health and save lives. KNCV was established in 1903 by civil society organizations. Presently our team includes over 400 professionals, working from a central office in The Hague, The Netherlands, and country offices in Africa and Central and South East Asia.

About The Global Coalition of TB Activists (GCTA)

The Global Coalition of TB Activists (GCTA) was formalised in 2014 to fill the gap of a global platform of people affected by TB to advocate for a people-centered, rights-based approach to TB response. The GCTA became a legally registered entity in 2018 and currently has over 300 members from around the globe. The GCTA envisions a ‘World Free of Tuberculosis’ with a mission to ensure that voices of TB-affected communities influence the global TB and health agenda.

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