

**NO MORE  
CRYING,  
NO MORE  
DYING.  
TOWARDS  
ZERO TB  
DEATHS IN  
CHILDREN.**



## FAST FACTS ON CHILDHOOD TB

- Tuberculosis (TB) is often not considered as a possible diagnosis and therefore goes undetected in children. This has made it difficult to assess the scope of the childhood TB epidemic.<sup>1</sup>
- At least half a million children become ill with TB each year.<sup>2</sup>
- Each year as many as 70 000<sup>3</sup> children die of TB - a curable disease that today should never take the life of a child.
- Children under 3 years of age and those with severe malnutrition or compromised immune systems are at greatest risk for developing TB.
- TB most commonly affects the lungs, but in 20% to 30% of cases in children it affects a different part of the body. Infants and young children are at special risk of having severe, often fatal forms of TB, such as TB meningitis, which can leave them blind, deaf, paralyzed or mentally disabled.
- In 2010 there were some 10 million children orphaned by the death of a parent from TB.
- Children are just as vulnerable as adults to developing—or becoming infected with—drug-resistant forms of TB that require a lengthy, costly treatment with often severe side effects.



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## **Imagine...**

being the parent of a child with tuberculosis (TB.)

Probably your child has been feverish and losing weight. Maybe she is coughing, and the cough is getting worse. She is constantly tired and unable to play with friends as before. She cannot understand what is happening to her.

They tell you at the clinic that she needs a TB test. This is not a simple matter. There is not a simple, painless test for TB in children. A doctor needs to insert a tube down her throat and then inject liquid in order to get a sample to test. This is frightening and painful for your daughter.

When the test comes back positive, you find out she will have to take four different medicines over six months.

You will soon find out the medicines don't come in the form of a syrup or chewable tablets. You will need to crush up the pills or encourage her to swallow them whole and find ways to help her to complete the treatment. It won't be easy, but you will have to do it. If all goes well she should be cured, but without proper treatment, TB often kills.

Imagine too how you feel knowing that your child is going through this ordeal because she caught TB from you. The vast majority of children with TB become ill through being infected by a parent.

Hundreds of thousands of mothers and fathers face this situation every year if they are fortunate enough to have access to diagnostic facilities and TB drugs for children. In many places children with TB have nowhere to go.



## WHY HAS CHILDHOOD TB BEEN SO NEGLECTED?

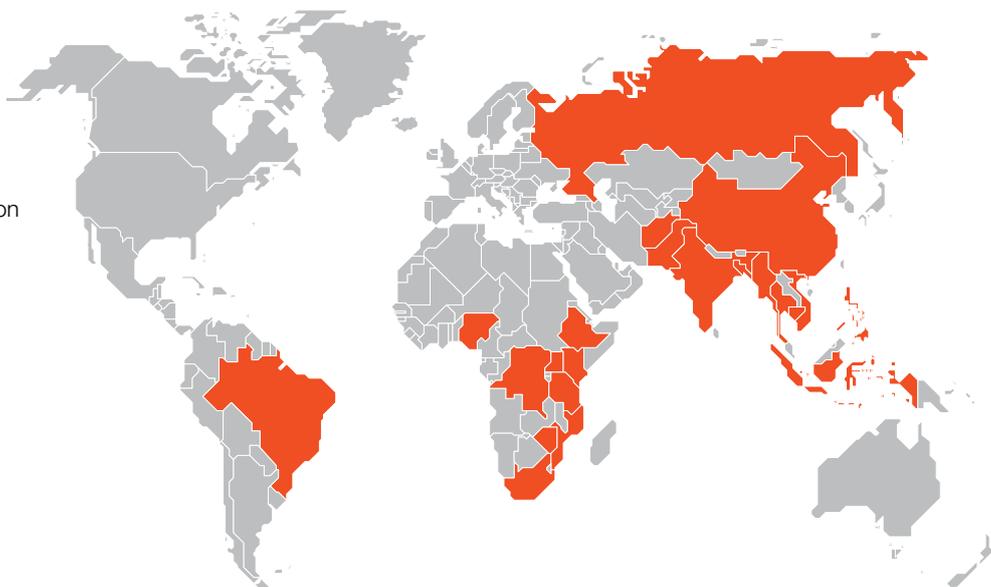
Until very recently childhood TB has not been a priority in public health and has remained essentially a hidden pandemic.<sup>4</sup>

All too often TB goes undiagnosed in children. While high-income countries now use sophisticated molecular tests to detect TB, most developing countries still use the method developed 130 years ago. The patient must cough up a sample of sputum, which is then checked under the microscope for the bacteria that cause TB. Young children generally are unable to produce a sample. Even if a child with active TB succeeds in providing a sample, it often contains no detectable bacteria. Compounding difficulties with diagnosis is the fact that children with TB have families that are poor, lack knowledge about the disease and live in communities with limited access to health care.

The challenge of diagnosing childhood TB has created a cycle of neglect, where insufficient awareness of the magnitude of the problem engenders a lack of public attention and funding. In addition myths about childhood TB abound. It is widely, and incorrectly, believed that all children with suspected TB need specialty care or expensive tests that are not available to all populations in the most heavily affected countries; and that TB treatment is more complicated or has more side effects in children, especially young children.

## 22 HIGH TB-BURDEN COUNTRIES

|                                  |                             |
|----------------------------------|-----------------------------|
| Afghanistan                      | Myanmar                     |
| Bangladesh                       | Nigeria                     |
| Brazil                           | Pakistan                    |
| Cambodia                         | Philippines                 |
| China                            | Russian Federation          |
| Democratic Republic of the Congo | South Africa                |
| Ethiopia                         | United Republic of Tanzania |
| India                            | Thailand                    |
| Indonesia                        | Uganda                      |
| Kenya                            | Viet Nam                    |
| Mozambique                       | Zimbabwe                    |



## TO MOVE TOWARDS ZERO TB DEATHS IN CHILDREN

Children with TB usually respond well to TB treatment and tolerate TB drugs very well—but first their illness has to be detected. The World Health Organization (WHO) and the Stop TB Partnership are calling on all public health programmes and health care providers to transform their approach to case finding—so that all infants and children with TB get high-quality care and the world can move towards zero TB deaths among children. Here is what we need to do.

**Start viewing childhood TB as a “family” illness.** Most children who become ill with TB have been infected by an adult—be it a parent or another person in the household. Any case of TB should prompt a careful assessment of the whole family’s TB risk. Children showing typical signs and symptoms of TB for their age group and who live with a person who has TB—regardless of whether a definitive diagnostic test is available - should be treated for TB. If there are no signs of illness, the child should be protected against TB with a six-month course of preventive treatment. Such protection is cheap and simple—a daily dose of a drug called isoniazid.

**Reach out to find all people affected by TB.** Every year, some 3 million people affected by TB are not diagnosed and treated according to international recommendations. Most are in the world’s most vulnerable groups: not just children but also adults living in remote rural areas or urban slums, migrant workers, displaced persons, prisoners and ethnic minorities. Many studies have shown that all those people could be receiving proper care—but only if there are efforts to actively look for people sick with TB in communities known to be at risk, and assist them in getting access to diagnosis and care. Only by reaching out to help all people with TB will we find all affected infants and children.

**Prioritize outreach in children living with HIV.** Active outreach is especially critical in countries where HIV and TB are prevalent. In those settings screening programmes should provide testing for both infections to all infants and children. Those who test positive for HIV should be tested for TB, and if TB diagnosis is confirmed then TB treatment should be started immediately. After two to eight weeks on TB

treatment, they should begin antiretroviral therapy (ART). Children who do not have active TB should immediately be started on preventive therapy with isoniazid, simultaneously with ART.

**Integrate maternal and child health services, HIV care and TB care into a seamless package.** Every country seeking to prevent deaths from TB among children living with HIV needs bold political leadership to integrate health services for women and children at every level through carefully developed and fully funded programmes. All pregnant women who are living with HIV should be examined for signs and symptoms of TB and provided with treatment if needed or preventive treatment with isoniazid. At every visit, babies and children who are malnourished or living with HIV should be checked for TB signs and symptoms. Making TB prevention and care an integral part of prevention of mother-to-child transmission of HIV, prenatal care, family planning and immunization services will prevent millions of unnecessary deaths among pregnant women and their children.





## REACHING FOR ZERO AT THE COMMUNITY LEVEL

An increasing number of studies are finding simple solutions for finding and treating more children affected by TB. In Bangladesh, in 2007, researchers from the Damien Foundation set out to determine whether raising awareness about the risk of childhood TB among health workers and teaching them to use a scoring card for TB symptoms would increase detection of childhood TB.<sup>5</sup>

The study compared childhood TB detection rates in 18 community health centres where health workers received training on childhood TB with detection rates in 18 comparable centres where no special training was provided. The result: the number of childhood TB cases detected more than trebled in the centres staffed by the newly trained health workers.

Another study, conducted in Karachi, Pakistan in 2011, engaged community members to help find TB cases, while also running a mass education campaign on the symptoms of TB.<sup>6</sup> The screeners used electronic scorecards on mobile phones to assess whether people in their community should seek a TB test; and then accompanied patients to the hospital or clinic. Each time screeners were successful in helping a person with TB reach diagnosis and care they received a cash incentive. One result was a 600% increase in detection of pulmonary tuberculosis among children.

## FOCUS ON TB AND PREGNANCY

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**More than half a million women of child-bearing age die from TB (including HIV-related TB) each year. The death of a mother leaves her child vulnerable to premature death.**

**Women living with HIV are highly susceptible to developing TB disease during pregnancy or soon after delivery.**

**TB is a leading infectious cause of death during pregnancy and delivery, especially among women living with HIV.**

**TB during pregnancy creates a high risk that babies will be born prematurely or have low birth weight.**

**TB during pregnancy increases the risk of transmission of HIV to the baby.**

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**OUR  
CHILDREN'S  
FUTURE:  
WHY WE  
NEED BETTER  
DIAGNOSTIC  
METHODS,  
DRUGS AND  
A VACCINE**

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**DIAGNOSTICS**



**Where we are:** Diagnosis is mostly done by microscopy, which is an inadequate test for TB in children. New rapid molecular tests, that are far more sensitive for detecting TB in children, are now becoming available, but the technology is costly and needs further testing. In addition, the traditional method of obtaining samples from children by inserting a tube down their nose or mouth is not ideal and may require an overnight stay in a hospital.

**What we need:** Cheap and rapid tests for TB that can detect active TB disease through a marker present in blood or urine and can be used in any health facility.

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**DRUGS**



**Where we are:** TB treatment requires taking a mix of three to four different drugs over six months; for multidrug-resistant TB, at least 18 months of treatment with combination of even more drugs, including at least 6 months of injections that can have severe side effects. Currently all available formulations are in the form of tablets that have to be crushed or swallowed whole—not an easy task for many children.

**What we need:** In the immediate future, child-friendly formulations; and within ten years, new drugs and regimens with shorter treatment time.

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**VACCINE**



**Where we are:** The current vaccine for TB, the Bacillus Calmette-Guérin (BCG), was discovered in the 1920s and offers only limited protection against severe forms of TB in young children but does not create lifelong protection. It is unsafe for use in children living with HIV.

**What we need:** A fully effective vaccine that protects children (and adults), including those living with HIV, against all forms of TB.

# GLOBAL SPENDING ON RESEARCH AND DEVELOPMENT OF NEW TB DIAGNOSTICS

## THE SEARCH FOR A QUICK TB TEST

The lack of a simple-to-use, inexpensive TB test is a serious barrier to reaching all children who need TB treatment. The quest to find such a test is on, but current funding is far too low.

**\$ 44 566 101**

Total funds made available in 2010 (US dollars)

**\$ 340 000 000**

2010 target for spending on diagnostic research in the *Global Plan to Stop TB* (US dollars)

**\$ 1.7 billion**

Total spending needed to meet the targets for new diagnostics of the *Global Plan to Stop TB* between 2011 and 2015 ( US dollars)

## STATEMENTS OF SUPPORT ON TB



**BAN KI-MOON**  
**United Nations Secretary-General**

Tuberculosis is a silent killer. We must raise the volume. TB hits poor, vulnerable and voiceless families. It takes the lives of tens of thousands of children every year and has struck down so many mothers and fathers. Millions of children are orphans because a parent died of TB. In these hard times, let us work even harder in the global fight against TB. We have the means to end these needless deaths. Let us act now.



**DR JORGE SAMPAIO**  
**UN Secretary-General's Special Envoy to Stop TB and former President of Portugal**

Every time I visit a country heavily affected by tuberculosis (TB) and look into the bright young faces of its children I feel a renewed sense of purpose in my role as the UN Secretary-General's Special Envoy to Stop TB. These children represent our future, but that future is dimmed by the menace of TB. We can't fully protect children against becoming ill with TB. But reaching every child who needs it with high-quality treatment, we can prevent the unthinkable – the loss of the life of a child to TB, a curable illness. I call on the world's leaders to commit to reaching the goal of zero TB deaths in children in the next five years.



**RACHEL ORDUÑO**  
**Patient Advocate**

For three agonizing years, I was misdiagnosed with flu, colds, allergies, respiratory infections, pneumonia, and asthma. My 3-year-old niece also suffered through surgeries to remove a recurring cyst. Only after I was correctly diagnosed, was her removed tissue tested and found positive for TB. We both started the daily medication treatment for active TB disease and five other family members took the preventive, twice-weekly dosing to neutralize the infection. I am living proof that TB is preventable, treatable and curable. But unless more is done to diagnose and treat men, women and children quickly and accurately, millions of lives will be lost.



**DR MARIO RAVIGLIONE**  
**Director, Stop TB Department, WHO**

TB is a preventable and curable disease, but every year half a million children suffer from TB and thousands lose their lives. In 2010, there were ten million orphans due to parental TB deaths worldwide. Progress on addressing this epidemic in children has been pitifully slow. There is an urgent need for the global health community to step up commitment and take concerted action towards ensuring that “not even one child dies from TB”. We must jointly accelerate efforts and invest all our energy to free the world from TB in children. WHO is committed to guiding these efforts.



**BLESSINA KUMAR**  
**Vice-Chair of the Stop TB Partnership Coordinating Board and representative for communities affected by TB**

TB is killing one child every 5 minutes! We do not see them affected but their ashes swirl all around us. How long will we use the usual argument that TB is different and continue to turn a blind eye. The success we have had fighting polio in India shows that when all players and stakeholders make a real effort we can put an end to unnecessary suffering and loss of lives. Now we must turn our eyes to TB and eradicate it. I am asking for a band of dedicated people to join me to call for 100% commitment to make 'Getting to ZERO' a reality.



**DR LUCICA DITIU**  
**Executive Secretary, Stop TB Partnership**

I wish to send a message to mothers everywhere. We have all gone through difficult nights when our children are sick and cannot sleep because they are feverish and coughing. They toss and turn in their beds and we feel desperate and helpless. Imagine your child is in this state because he or she has TB. Imagine the child coughing and coughing and crying — and this goes on and on for weeks and weeks. TB should not make any child suffer or die. We know how to cure TB and we know how to prevent it, and both are cheap interventions. Any child dying of TB in the year 2012 is an affront to our civilization. Children do not have the power to speak for themselves or push for action. We all have to do it! Otherwise, none of us can look our children in the eyes.



**DR STEVE GRAHAM**  
**Associate Professor of International Child Health, University of Melbourne, Australia and Chair of the Childhood TB sub-group of the Stop TB Partnership's DOTS Expansion Working Group**

It is very encouraging that TB in children is gaining recognition as an important public health challenge worthy of far greater attention, and this change positions us to address issues that have languished up until now. First, we have interventions that can prevent TB deaths in children — but many countries are not using them in practice. That has to change. Second, we must ensure that children are included in crucial research to develop new and better diagnostic tests and drugs for TB.



**DR DENIS BROUN**  
**Executive Director, UNITAID**

TB is a curable disease that continues to kill, largely due to the lack of innovation in TB treatment and low demand in markets. As in other disease areas, children's treatment needs for TB have been under-recognized. And yet, the impact of TB in children is real and devastating, with half a million children needing treatment today. To address this gap, UNITAID has catalyzed the development of a market for quality-assured paediatric products by providing close to US \$10 million for the supply of over one million treatments and by investing in the WHO Prequalification Programme. But more action is required to make child-friendly TB medicines available to all children in need, at low cost and supplied faster. UNITAID is taking the lead in developing tools to measure the need for products and the market shortcomings for paediatric diagnostics and medicines so as to boost targeted action and better support all stakeholders working to increase children's access to the products they need and to which they have a right.



**DR CAROLE PRESERN**  
**Director of the Partnership for Maternal, Newborn & Child Health**

When pregnant women become sick with TB there is a strong chance they will die during childbirth. The risks to their children are equally severe. Some might be premature; others are at greater risk of low birth weight and subsequent mortality. In addition, mothers living with HIV who have TB are more likely to transmit HIV to their babies. If we are to achieve the Millennium Development Goals we must act now.

# FIGHTING CHILDHOOD TB AT NATIONAL- AND COMMUNITY-LEVELS

## WHAT DIFFERENT PLAYERS NEED TO DO

### NATIONAL TB PROGRAMMES

- Develop childhood TB guidelines and make diagnosis and treatment of childhood TB a priority
- Evaluate all children who have been in contact with adult TB patients to determine if they need treatment for active TB or preventive treatment with isoniazid
- Train all health workers to recognize TB symptoms in children; ask about contact with people affected by TB at each visit and take a family-based approach to evaluating TB risk
- Offer HIV testing in the context of TB care
- Routinely record and report numbers of cases of TB in infants and children
- Conduct research aimed at finding the most effective ways to improve and build childhood TB programmes

### HEALTH WORKERS WHO CARE FOR SICK CHILDREN

- Stay alert to symptoms typical of TB and make needed referrals

### HEALTH WORKERS IN THE PRIVATE SECTOR

- Learn about TB and follow the government guidelines for prevention, diagnosis and treatment
- Report to the national TB programme each child diagnosed with TB

### HEALTH CENTRES PROVIDING PRENATAL AND OBSTETRIC CARE

- Evaluate every pregnant woman for TB risk and provide needed referral or treatment
- Provide preventive treatment with isoniazid to all pregnant women living with HIV
- Evaluate newborn infants for TB as soon as possible after birth if the mother had TB during pregnancy
- Liaise with the national TB programme

### IMMUNIZATION SERVICES

- Evaluate HIV-infected and malnourished children for TB signs and symptoms at every opportunity
- If TB is suspected, refer the child to the national TB programme

### HIV PROGRAMMES AND CENTRES

- Train staff on TB prevention, diagnosis and treatment and ensure they understand these are priorities for saving lives
- Create strong links with maternal and child health programmes and the national TB programme
- Routinely evaluate all pregnant women for TB risk as part of prevention of mother-to-child transmission services
- Ensure children with HIV are routinely screened for TB as part of standard clinical care
- Provide preventive treatment with isoniazid to all patients living with HIV who are at risk of TB but do not have active TB disease

### PEOPLE IN TB-AFFECTED COMMUNITIES

- Seek prompt medical attention for any child or adult who has TB symptoms
- Bring any child who has been in contact with a person sick with TB to a health centre for TB testing





## ROADMAP TOWARDS ZERO TB DEATHS IN CHILDREN

### 2015

All national TB programmes and linked health centres implement the actions on childhood TB outlined on page 10

All HIV centres evaluate pregnant women and their infants for TB risk

All research studies on new TB diagnostics and drugs include pregnant women and children among participants

More accurate estimates of the number of TB cases and deaths among children available for all countries

Funding for research on TB diagnostics, drugs and vaccines increase to a total of US\$ 2.5 billion dollars per year, as called for in the Global Plan to Stop TB<sup>7</sup>

### 2020

A quick inexpensive “point of care” TB test that provides accurate diagnosis in children available worldwide

Shorter, child-friendly TB treatment and preventive treatment available worldwide

A new vaccine able to prevent TB infection and disease in children and adults is on the market

## TAKE ACTION AGAINST CHILDHOOD TB

Sign the Call to Action. In March 2011, experts on childhood TB from around the world gathered in Stockholm, Sweden to develop a roadmap for addressing childhood TB with the goal of reaching zero TB deaths in children. Together they launched a Call to Action for Childhood TB<sup>8</sup>

### **Please add your voice to the Call at:**

[www.stoptb.org/getinvolved/ctb\\_cta.asp](http://www.stoptb.org/getinvolved/ctb_cta.asp)

### **Donate now to the Stop TB Partnership.**

Our TB REACH projects are using innovative approaches to finding, diagnosing and curing more children with TB. For more information, link to [www.stoptb.org/getinvolved/donate.asp](http://www.stoptb.org/getinvolved/donate.asp)

### **To find out more about TB, visit:**

WHO Stop TB Department  
[www.who.int/tb/en/](http://www.who.int/tb/en/)

Stop TB Partnership  
[www.stoptb.org](http://www.stoptb.org)

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#### **Note**

- 1 Nelson LJ and Wells CD, *Global epidemiology of childhood tuberculosis*. Int J Tuberc Lung Dis, 2004, 8(5): 636-647
- 2,3 The World Health Organization is preparing new estimates that will be released later in 2012.
- 4 *Children and Tuberculosis: Exposing a Hidden Epidemic*, 2011, Action Project, [http://c1280352.r52.cf0.rackcdn.com/childrens\\_tb\\_0811v2.pdf](http://c1280352.r52.cf0.rackcdn.com/childrens_tb_0811v2.pdf)
- 5 K. Talukder et al, *Intervention to increase detection of childhood tuberculosis in Bangladesh*. Int J Tuberc Lung Dis, 2012, 16(1): 70-75
- 6 Khan A et al, *Engaging the private sector to increase tuberculosis case detection: an impact study*, in press 2012
- 7 *Global Plan to Stop TB 2011-2015*, 2010, Stop TB Partnership, <http://www.stoptb.org/global/plan/>
- 8 *Childhood Tuberculosis: Progress Requires Advocacy Strategy Now*. Sandgren A, ERJ, 2012 (In press)

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## WHAT IS TB?

Tuberculosis (TB) has affected people all over the world for millennia.

TB is infectious and spreads from person to person through the air. When people with infectious TB cough, sneeze or spit, they propel the germs that cause TB into the air. A person needs to inhale only a few of these germs to become infected. TB can infect any part of the body, but most often it attacks the lungs.

One third of the world's population has latent TB, which means they have been infected by TB without being infectious to others. Even when a person develops active disease, the symptoms may be mild for many months, which leads to delays in diagnosis and treatment and spread of the disease to others.

Most people with TB can be cured by taking a six-month course of drugs costing about US \$25. When people can't or don't take all their treatment, TB bacilli become resistant to them and multidrug-resistant TB (MDR-TB) can develop. MDR-TB takes longer to treat and can only be cured with second-line drugs, which are up to 1000 times more expensive and have more side effects.

Extensively drug-resistant TB (XDR-TB) can develop when people can't or don't take all treatment with these second-line drugs. XDR-TB is virtually untreatable.

Both MDR- and XDR-TB can spread from person to person. The best way to stop emergence of drug resistance is to ensure that every person with TB has access to accurate diagnosis, effective treatment and a cure.

People living with HIV are 20 to 30 times more likely to develop TB than people free of HIV infection. Without treatment, the vast majority of people living with HIV who are sick with TB will die within a few months. TB is responsible for one in four AIDS deaths.

People with TB often suffer from discrimination and stigma, rejection and social isolation. It mainly strikes people living in poverty since conditions such as malnutrition, overcrowding, poor ventilation and exposure to indoor smoke create high risk for the disease. And TB is a major cause of poverty because affected people are often too sick to work, and they and their families may have to pay for treatment. All too often children who are sick with TB or have a parent sick with TB lose educational and future economic opportunities.

**Stop TB Partnership**  
[www.stoptb.org](http://www.stoptb.org)

**World Health Organization**  
**Stop TB Department**  
[www.who.int/tb](http://www.who.int/tb)

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