

## Talking to your patients about latent TB infection (pediatric patients)

**Purpose:** This document offers information for providers who are talking to patients or their caregivers about latent TB infection (LTBI).

- The first part is a guide for counseling your patients about tuberculosis, LTBI, testing and treatment.
- The second part lists common patient questions and suggestions for how to respond.

**Instructions:** Each section addresses an important question or topic. Use the patient's answers or information to decide if the particular topic is relevant. You might need to use all or only a few of the sections.

### PART 1: Talking points

#### ***What do you already know? What concerns do you have?***

- Tell me what you know about TB.
- Then I can focus our time on talking about the parts you do not know or the areas where you may have some misconceptions.

**(Based on the patient's response, SKIP AHEAD to the topics needed)**

#### ***What is tuberculosis (TB)?***

- Tuberculosis, or "TB," is a **serious disease** caused by bacteria. It spreads from person to person through the air and **usually affects the lungs but can also affect any other part of the body.**
- When a person who is sick with TB coughs, they **send TB germs into the air.** If others breathe in the TB germs, **some may get sick.**
- You may have heard of TB before, but you might not know **how common it is.** Over 2 million Californians are infected.

#### ***What is the difference between latent TB infection (LTBI) and active TB?***

- TB germs can **hide in the body for years.** This is called "latent TB infection" or LTBI.
- People with latent (or "hidden") TB infection **do not feel sick,** and they **cannot transmit TB** to others.
- Unfortunately, some latent infections will eventually cause disease. After being "latent" or "hidden" in your body for many years, **latent TB infection can suddenly become active.** Young children, under 15 years of age, are more likely to develop TB disease soon after exposure to TB than older children and adults.
- Active tuberculosis disease has **serious symptoms,** and can include **fevers, night sweats,** extreme tiredness, unintended weight loss, and a **prolonged cough with or without blood.** Young children do

not necessarily have these symptoms and may present with other symptoms such as change in mood or irritability.

- In some cases, people with active tuberculosis **become severely ill and die. Young children less than five years of age are especially vulnerable to severe TB disease.**
- People with **active TB disease** are infectious, and **can transmit the germs to family or friends.** However, **small children** (less than 5 years of age) are **less likely** to transmit disease to others. Children **5 to 15** years of age can transmit disease depending on how sick they are.

### ***How does latent TB infection (LTBI) progress to active TB?***

- Most TB disease occurs in people who **had latent infection for a long time**, and **never knew** they were infected.
- **Certain conditions** such as young age, diabetes, kidney disease, immune compromise, cancer, and smoking **increase chances of progressing to active disease** once infected.

### ***How do you know if you have LTBI? Who should be tested?***

- Fortunately, there is a **simple blood test** to help us determine if your child has been exposed and has TB infection.
- If your child has one or more of the following **risk factors**, s/he should get tested.
  1. Was s/he **born in** Africa, Asia, Central or South America, Eastern Europe or other countries with elevated rates of TB? Or has s/he **traveled to or lived in those areas** for longer than a month?
  2. Has s/he ever been in **close contact with anyone who was sick with TB disease**? Even if it was long ago, your child may still be at risk for infection because the TB germs can hide in the body for many years.
  3. Does he/she have a **condition that affects the immune system** or is s/he taking any medications that impact the immune system (TNF-alpha inhibitors such as infliximab or etanercept, methotrexate, or steroids)? Is s/he being treated for HIV or cancer?
- I want to help **protect your child from TB**. So if any of these risk factors apply to your child, we should get him/her tested.
- If you know anyone else, including yourself, who may have any of these risk factors, please **encourage them to get tested**. It might save their life, your life or your child's life.

### ***Who should be treated for LTBI? How do I know treatment is right for me?***

- Most people with a **risk factor for infection** and a **positive TB test** should be treated.

- If your child's blood test (or skin test) comes back positive for TB infection, we will **check him/her for symptoms** and **do a chest x-ray to make sure that s/he does not have active TB disease**. If the x-rays are normal, your child has LTBI, and probably should be treated.
- If your child is at high risk for LTBI and tests positive, **we can protect him/her from getting TB disease by treating his/her infection now**. While treatment of latent TB infection is relatively straightforward, treatment of active TB disease is more challenging, involving more drugs taken for a longer time. Therefore, we strongly recommend getting treated now for LTBI.
- **Finding and treating LTBI early protects your child from getting sick and protects others**, especially the people who your child spends time with, from getting infected. By working together with patients and their communities, I hope we eliminate TB in our lifetime!

## **PART 2: Frequently asked questions, with suggested responses**

### ***TB infection and testing***

**“I thought TB doesn’t exist in the U.S. anymore. How could my child get it?”**

TB does exist in the U.S. Anyone can get TB, but some people are more at risk than others. People have a higher risk of TB if they:

- were born in or traveled to or lived longer than a month in Africa, Asia, Central or South America, Eastern Europe, or other countries with elevated rates of TB
- have a weakened immune system
- spent a lot of time with a person with infectious TB

**“I thought TB is hereditary so how can it be prevented?”**

There are many myths about TB. Some people think it is hereditary, and others believe it can be caught from cups, utensils or touching someone with TB. In fact, TB can only be caught if you breathe in the germs when a person with TB disease coughs, sings or speaks. The reason TB can cluster in families is because families live or spend a lot of time together and therefore breathe the same air; it is not hereditary.

**“Why should my child be tested for LTBI?”**

Getting tested will show if your child has LTBI, and there are treatments available. LTBI treatment protects your child from getting sick in the future. Similar to getting vaccines to prevent a disease later on, treating TB infection prevents your child from getting sick with TB disease.

### ***BCG vaccine***

**“My child had the vaccine when s/he was a child so how can s/he get TB?”**

The TB vaccine (called BCG) does not work in all cases, nor does it protect your child for his/her whole life. It is most effective in young children against more severe forms of TB.

**“I think my child's test result must be a false positive because s/he had a BCG vaccine.”**

There are sometimes false positive results with the TB skin test, but not with the blood test. We can do a TB blood test to look for infection. If your child has a positive TB blood test then s/he is likely infected with TB, even if your child was vaccinated.

### ***TB treatment***

**“Why should my child take medication if s/he is not sick?”**

The medication kills the TB germs in the body before they have a chance to “wake up” and make your child sick. TB germs are easier to kill when they are not active and there are fewer of them. By getting rid of the germs now through LTBI treatment, you’re protecting your child and your family from getting active TB, which can do a lot of damage to the body.

## ***TB treatment (continued)***

### **“I have heard treatment takes a long time!”**

TB is a slow-growing bacteria, so treatment of TB infection takes longer than antibiotics you take for a typical pneumonia or minor infection. But it usually takes less time and less drugs to treat latent TB infection than TB disease, which is why we recommend getting your child tested and treated for LTBI if s/he is at risk. LTBI treatment can often be completed in 12 doses, or 3 months. However, if a person doesn't take all their medicine, TB germs may multiply and be harder to kill. So it is important to treat the infection fully now to prevent TB disease later on.

### **“My child feels fine now. So why should s/he take medication?”**

It is important to stop the germs before the germs grow, spread, and cause active TB disease. People with active TB disease can get very sick and can spread TB to other people. Approximately 10% of people with TB disease die. If your child gets treated, you can protect him/her and the other members of your family from getting sick.

### **“Everyone I know has (latent) TB/a positive test result so why does it have to be treated?”**

It is important to stop the germs before they become active because then the germs grow and spread. People with active TB disease can get very sick and can spread TB to other people. If your child gets treated now, you can protect him/her and the other members of your family from getting sick.

### **“Can the LTBI medications harm my child? Is it better to wait to treat him/her when s/he is older?”**

The side effects of the medication are usually less harmful to your child than the disease itself. The chances of having a serious side effect are less than the chance of getting sick with TB disease. Plus, LTBI treatment is very well tolerated and safe for kids. In fact, kids have fewer problems taking LTBI medications than adults do, so it's actually easier to get them through treatment before they get older.

## ***Other concerns***

### **“What will happen to my child if people find out s/he has LTBI?”**

Your child's test results will be confidential. Children with LTBI do not have to miss school or daycare.

### **“Will my child die? Isn't TB incurable?”**

TB is curable. We have good medications to help remove the bacteria from your child's body. It is much easier to treat TB infection when s/he has latent, vs. active disease, which is why we recommend getting tested and treated for LTBI if your child or you are at risk. However, if your child develops active disease, your child's doctors and the health department will find you medicines and support you through treatment.

### **“If my child has TB, does that also mean s/he has HIV?”**

Absolutely not. In some parts of the world, people with one disease often have the other, but having TB does not mean your child has HIV. As part of your child's evaluation for TB, we can do a simple blood test to ensure your child is HIV negative.