



TI KAY

WE FIGHT
TUBERCULOSIS
AND HIV IN HAITI

2018

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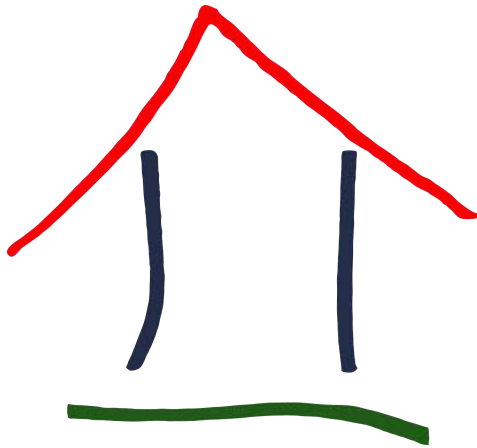
**Tuberculosis is a disease
you get just from
breathing.**

**If someone else has TB,
they breathe out TB and
you can breathe it in.**

It's as simple as that.

TB then spreads among families that live in crowded homes or who don't have enough to eat. It's a disease that can come on insidiously, taking away energy and pounds, turning patients into emaciated, living ghosts.

TB is curable, but for those who make less than a dollar or two a day, even accessing free care can be out of reach.



Ti Kay (*pronounced Tee-Kye*) means “Little House” in Haitian Kreyol. TB was traditionally the “malady of the little house,” where those with the disease were quarantined.

In Haiti, it has become the disease of those with the littlest of houses, or no house at all.

Ti Kay aims to remove the myriad of barriers to treatment for patients with TB and HIV in Haiti.

TI KAY REMOVES BARRIERS TO TREATMENT

Nutrition:

Food is itself medication. Many patients arrive weighing less than 70 or 80 pounds, as adults. Each patient is assessed personally by a community health worker. Their weight gain and food intake is tracked and adjustments made.

Oxygen:

We have a team dedicated to oxygen delivery in patient homes. This team is responsible for delivery, administration and titration of oxygen in patient homes. This program is the first in Haiti to train and maintain oxygen attendants and have a program allowing oxygen-dependent patients to live at home. The team's training in assessment, titration and management of oxygen has been through apprenticeship with expat volunteers both in Haiti and remotely via our telemedicine program. Keeping everyone supplied with the oxygen they need is a labor intensive and costly task.

Adjunct Medications:

Medications are often out of reach for our patients. Fortunately, TB and HIV medications are free, but the medications needed for opportunistic infections as well as diseases that put them at risk for TB, such as diabetes, may not be in reach. Medication regimens are followed by the telemedicine project and patients are provided needed medications available if needed with a valid prescription.

Telemedicine & Medicine Adherence:

TB medications are standardly taken for 6 months or longer. Adherence to long courses of medications is difficult and can lead to medication failure and drug resistance. One means of ensuring adherence traditionally has been Directly Observed Therapy (DOTS). However, this isn't an effective option, given the number of patients, who may live transiently in different locations, where patients cannot afford to come to the clinic, live in areas accessible only by foot, where disruptions like strikes can interrupt care and transportation. Instead, patients have regular visits by a community health worker (CHW), often daily, to directly observe treatment and to ensure patients eating. The CHW sends pictures that are "virtually seen" by medical personnel on the same day. In some cases, patients may send in pictures of themselves to show adherence or for medical concerns. This system allows the program managers and clinicians to oversee the CHWs and ensure patients are improving, through regular videos, audio messages, texts and photos. This creates a collaborative relationship between a regular clinician, often in the US, and a CHW, some of whom are not literate. Medication compliance is tracked in the database and missed medications or appointments are followed up on immediately.

Privacy is strictly maintained in the use of these photos.

Community
Health Workers:

Ti Kay works with past patients and their family members to train and support them as community health workers. These workers visit and call patients at their homes to ensure medication compliance and weight gain. They assess each patient's home situation and their individual barriers to completing treatment. Community health workers also provide encouragement and emotional support, as well as food and help to overcome barriers to care. They are uniquely qualified to do so because they have experienced TB/HIV diagnosis and treatment themselves or they have cared for a family member who did.

Health
Education:

Our organization focuses on training and supporting local caregivers, which provides work opportunities for the community. We have made hours flexible for team members to pursue further education in nursing and IT. We have run workshops for community health workers. Nurses also receive one on one training with expat nurses to increase their assessment skills.

Patient
Education:

We use smartphones to educate our patients, their families, and communities. Videos have been created by Ti Kay volunteers to explain to patients in Kreyol the importance of medication compliance and how noncompliance breeds resistance. Video is the best form of education for our patients, as many are unable to read. Community health workers educate patients and their families about how to safely live with their diagnosis and the importance of adhering to their medication regime.

In 2018, our team:

- Completed 4,783 visits to patients at home
- Delivered 86 bottles of oxygen in addition to oxygen via concentrators, generators to power concentrators and fuel to power the generators where needed.
- Enrolled and supported 32 children in school whose education had been stymied by HIV or TB
- Housed 11 patients and their families (including 14 children) who otherwise did not have a safe place to live and heal.



Ti Kay Schools Program

Tuberculosis and HIV take more than just lives,
they steal opportunity.

Ti Kay's Schools Program was established in 2010 to address the educational barriers faced by children suffering from Tuberculosis and or HIV, or by children who have lost a parent to these diseases.

They are provided tuition, uniforms, and books for the school year. Kids are tracked year after year for completion of the school year and continuance of their scholarship.



Lives Changed

He was a quiet man. He was hospitalized for two months. No one visited. No one knew much about him. He did not react when he was told he had HIV or TB. He nodded; he understood. He said he would take his medications every day for his whole life.

When he was discharged home, a community health worker was assigned by the clinic to accompany him. She's seen many homes where the poor with TB live. She was surprised. She took photos with her cellphone of the dirt floor, the simple bedding spread on it, and the leaking tarp.

She also took photos of the three children in the tent. The eldest, maybe not even a teenager, had watched over the others. Their mother had died, likely from HIV, a few years before. The community health worker saw why he had been so accepting of his diagnosis and committed to his medications - these three children.

His family was enrolled in our school program. He had very little money; he did not have a mattress, but after their first day of school he came with 3 pictures he had paid to have taken: his children in their school uniforms.



Her tiny frame carried as much weight as hefty newborn. She was 5 years old. TB had spread throughout her body. Malnutrition had let it spread quickly. Diagnosis of TB is not easy in children. She was referred to our TB clinic near death. With a tube feeding her through her nose and ground up daily medications, she improved. She was able to go home. There, her father could never leave her other 5 siblings and his work. He was late coming for her medication appointments. He wasn't sure at first when she was doing better, if she really needed these medications. She then relapsed and he brought her back as sick when she first arrived. We did not know if she would survive.

Her sister, just 15, was asked by her family to stay with her. She missed the rest of her school year as she stayed by her sister's side. The family had lost a lot of money by their father losing days from work and having to pay for transport to the city from their rural home.

It wasn't clear if he would be able to pay for her to repeat the year next year, as she was already 15 years old.

Our patient slowly improved with the tube feeding her. This time she went home accompanied home by a counselor. This community health worker crossed the river that did not have a bridge and reached their home that cell phone reception did not. He would return regularly with food and medications and watched her become a normal child again among her many siblings and cousins.

Both of these girls were enrolled in school this year. We were able to pay for their tuition fees and uniforms directly. Their counselor continued to visit and track their school progress. They stay in the homes of members of our team to help them get through school.





He was born with HIV. He lost his mother early in life and his father was not very attentive to him, at times he was abusive. At the age of 13 he found himself ill.

He had nowhere to turn for treatment as he could not afford to pay for testing or treatment. Finally, he found Ti Kay. He was diagnosed with TB and HIV and started on meds for both. After getting started on TB meds and antiretrovirals. He began to feel better and as teenagers often do he began to feel invincible and would neglect to take his medications. He would again fall ill, but this time he had developed resistance to the medications that were being used to treat him. His medications were changed to treat him and further efforts were made to keep him on his medications. He was provided supplemental nutrition as needed to facilitate healing as he was not receiving food at home. He completed his TB treatment, but he will require a lifetime of daily antiretrovirals so his medication compliance continued to be of utmost importance in keeping him well.

He was one of our first patients enrolled in the telemedicine program as he continued to require additional supervision to make sure he took his meds daily. With his health stabilized he was also able to start school.

He also helps other patients, caring for others that have the same needs that he once did.

His personal experience with TB and HIV makes him as uniquely qualified to help others who are facing hopelessness with the same illnesses.

How are donations used?

*Supporting the local economy in Haiti is important to Ti Kay.
In 2018, 92% of the money donated to Ti Kay was spent in Haiti.*

8% to purchase and deliver oxygen to patients

9% to remove roadblocks to care. This includes, including food*, adjunct medicines, medical care, transportation to medical appointments, safe housing and other supplies used to care for patients.

*(80% of the food Ti Kay distributes to patients is donated directly to Ti Kay and is not accounted for in this accounting of dollars spent)

54% to support home visits where patients receive counseling, physical therapy, education on their disease, medication adherence support, assessments, and oxygen monitoring

8% for rent on office space and secure supply storage in Port-Au-Prince from which daily patient visits are coordinated

13% for scholarships for kids who have had their lives affected by TB/HIV

8% of funds were used for administrative expenses:

6% for banking and transaction fees, needed given banking infrastructure in Port-Au-Prince

2% for website fees, tax preparation, and incorporation fees.

No money from grants or donations to Ti Kay in 2018 were used to pay expatriate salaries, expenses or travel. Ti Kay is run entirely by volunteers, who donate their time and skills to support the work of local Haitians caring for members of their community.

All patients receive care, free of charge.





Megan Coffee, MD, PhD (DPhil) completed her undergraduate studies at Harvard, going on to receive a PhD (DPhil) from Oxford in Mathematical Models of Infectious Disease (HIV) Transmission and an MD from Harvard, and is board certified in internal medicine and infectious diseases. Dr. Coffee volunteers her services running the program. The clinic's contributors are recruited from the local population and trained by Dr. Coffee, many of whom are former patients who have recovered from TB or HIV-associated illnesses and want to help their community. Indeed, the Haitian nurses and service providers at Ti Kay are proud to be making a difference for their country.

Ti Kay, Inc. is a 501(c)3 organization,
All donations can be tax-deductible in the United States.



For Donations:
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