Dear Friends and Colleagues - Partners in the Caritas Internationalis HAART for Children Campaign

We thank you once again for your dedication and effective advocacy and service efforts to advance the cause of early diagnosis and treatment for mothers and children living with or vulnerable to HIV infection. The release of this issue of the HAART for Children Newsletter coincides with World TB, observed annually on 24 March. By adopting this focus, we are calling for more attention on childhood TB: we want children to be protected from TB and we want to avoid their deaths. TB is curable and preventable, even in children.

In this issue, with the help of the World Health Organization (WHO) Global TB Department, we offer updated information about the extent of TB in the world, with special attention to children living with or vulnerable to the disease. We also share the WHO Strategy, “Reach, Treat, and Cure Everyone,” with the aim to significantly reduce the number of people infected with TB but are not diagnosed or treated and thus run the risk of becoming sick with this disease.

We also have the privilege to share the testimony of Norah, a mother of five children, who living with HIV. Norah was successfully treated for TB infection with help from the Uzima programme at the Jesuit parish of St. Joseph the Worker, in Kangemi, a very poor settlement on the outskirts of Nairobi, Kenya. We are most grateful to Norah for sharing her story with us, an to Danielle Vella, of AJAN, the African Jesuit AIDS Network, for her permission to print this story which also will appear in the upcoming AJAN Newsletter.

We also present two Good Practice Models: one from Caritas Ukraine which engaged young people in educating the public about risks of TB infection and the need for early diagnosis and treatment and another from the Catholic Relief Service (a USA-based member organization of Caritas Internationalis) programme in Mali, which is facilitating cooperation between faith-based organizations and the national government there as they advance efforts to stop the spread of HIV in this country.

Let us continue our efforts to make children safe from both HIV and TB! Let us never ignore or forget Pope Francis’ compelling pastoral analysis of modern-day global trends as well as his plea to transform ourselves and the world into the
vision that was shared with us by Our Lord Jesus Christ:

In our time humanity is experiencing a turning-point in its history, as we can see from the advances being made in so many fields. We can only praise the steps being taken to improve people’s welfare in areas such as health care, education and communications ... At the same time we have to remember that the majority of our contemporaries are barely living from day to day, with dire consequences. A number of diseases are spreading. The hearts of many people are gripped by fear and desperation, even in the so-called rich countries.

The Pope loves everyone, rich and poor alike, but he is obliged in the name of Christ to remind all that the rich must help, respect and promote the poor. I exhort you to generous solidarity and a return of economics and finance to an ethical approach which favors human beings.

Msgr. Robert J. Vitillo,
Special Advisor on Health and HIV, Caritas Internationalis
Ms. Francesca Merico,
Volunteer Coordinator, HAART for Children Campaign

1 Pope Francis, Evangelii Gaudium, #52 and 58

Every year, on 24 March, the world observes World TB Day (WTBD). This day aims to raise public awareness that tuberculosis (TB) today remains one of the most serious epidemics in much of the world. In fact, it causes the deaths of nearly 1.5 million people annually, mostly in developing countries. Every year an estimated 9 million people are newly infected with TB. In addition, 3 million cases are not diagnosed, not treated, and thus are not registered by national TB programmes or counted in global statistics. The overall theme for World TB Day 2015 is “Reach the 3 Million”. The main message for this year is "Reach, Treat, and Cure Everyone”.

Scale of the Problem

According to WHO, one-third of the world’s population is infected with TB. Out of this population, 1 in 10 will develop TB during their lifetime. Among those missed are those most vulnerable to falling ill with TB including very poor and/or malnourished or undernourished people, people living with HIV/AIDS, children and women, migrants, prisoners, refugees and internally displaced persons, miners, the elderly, ethnic minorities, indigenous populations, drug users and homeless persons.

During 2013, an estimated 480,000 people developed multidrug-resistant TB (MDR-TB), and extensively drug-resistant TB (XDR-TB) was reported by 100 countries. There is slow progress in tackling drug-resistant TB: 3 in 4 drug-resistant TB cases remain without a diagnosis, and only 97,000 patients were started on MDR-TB treatment last year.

Children and TB

The most recent estimates of the WHO indicate that at least 1.5 million children become ill with tuberculosis each year and that, on an annual basis, up to 80,000 children die of TB. Children under 3 years of age and those with severe malnutrition or compromised immune systems are at greater risk for developing TB. Moreover, in 2010, some 10 million children were identified as having been orphaned as a result of deaths cause by TB for one or both of their parents.

On the occasion of World TB Day 2015, Caritas Internationalis is calling for more attention to childhood TB. We want children to be reached, treated and cured. Yes, since TB is curable, it can be treated in 6 months, but only IF it is properly and
promptly diagnosed! This “ask” on the part of Caritas is consistent with our ongoing “HAART for Children Campaign”, through which we promote early diagnosis and “child-friendly” treatment of children living with HIV. The fact is that TB remains the greatest cause of death among such children. And let us not forget their mothers … given the intimate bond between mother and child, both TB (though airborne means) and HIV (during pregnancy, the birth process, and breastfeeding) could be transmitted from mother to child. However, when mothers are diagnosed and treated, they are much less likely to pass the infections of TB and/or HIV to their children.

What Is Needed to Realize the Aim of World TB 2015, Especially With Regard to Paediatric TB?

We recently met with Dr. Malgorzata Grzemska who serves in the WHO’s Global TB Programme in Geneva. She is responsible for coordinating technical assistance to regions and countries in implementing Stop TB Strategy, development of treatment policies on TB and Childhood TB. Dr. Grzemska updated us about progress and challenges around childhood TB, and about advocacy on childhood TB. “In the past years,” she said, “a lot has been done: from the Call to Action for Childhood TB by the Stop TB Partnership in 2011; the focus on childhood TB on occasion of WTB in 2012; the launch of The roadmap for childhood TB by the Childhood TB Subgroup in 2013; and the publication of the Childhood TB training toolkit by WHO and the International Union against Tuberculosis and Lung Disease (the Union). However, a lot still needs to be done”.

Here Are Some of the Urgent Needs Shared by Dr. Grzemska:

Better diagnostic tools for children are urgently needed:
Until recently childhood TB was a hidden pandemic, mainly because it still has been very difficult to diagnose in children. According to WHO, while sophisticated test is utilized in high-income countries, health care workers in developing and poor 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 presence bacteria that cause TB. Often young children are unable to produce enough sputum to yield an accurate test result and when they do produce a sample, it often contains no detectable bacteria. We need to develop tests that can be used on such body fluids, for example, as urine or blood.

Health care workers must be trained on how to promptly detect TB in children and in pregnant women:
Since the majority of children living with TB and HIV/TB coinfection live in poor settings and come from poor families who have a limited access to health care, we need to provide testing at sites that are close to their homes (optimally, at village level) and we need to train village health workers to diagnose the disease and to monitor the treatment of TB at the local points of care. Moreover, these health care workers need to be trained to detect TB in children and pregnant women even when tests are not available. For example, it is very important to pay special attention to children and mothers who suffer from malnutrition and HIV, TB is a co-infection in many such patients. In 2014, WHO and the International Union against Tuberculosis and Lung Disease released the Childhood TB training toolkit. These guidelines and training material for health care and community care workers should be shared as much as possible in order to facilitate extensive outreach to the majority of people who are living with or vulnerable to TB disease.

Childhood TB should be viewed as a “family” illness:
Health care and community care workers should look at childhood TB as a “family” illness since the majority of children living TB contract the infection from a member of their own families. Yes, 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 risk of TB infection.

Outreach to children living with HIV should be prioritized:
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 begin antiretroviral therapy (ART). Children who do not have active TB should immediately be started on preventive therapy with isoniazid preventive therapy, at the same time they begin ART.

Outreach to women living with HIV and to pregnant women is needed:
More than half million women of childbearing age die from TB (including HIV-related TB) each year. Women living with HIV have a higher chance to develop TB disease during pregnancy or soon after delivery. TB is a
The Caritas network includes 164 national member organizations, operating in more than 200 countries and territories of the world. In addition, in each country, there may be several local (diocesan) Caritas agencies. This network participates in and benefits from ongoing exchange between national and local Caritas organizations. This is facilitated by the 7 regional Caritas structures and by the Caritas Internationalis General Secretariat and International Delegations, which assist members to advocate at regional and global levels (UN agencies and Regional Economic and Parliamentary structures, among others).

The overall network is highly engaged in providing a person-centred response to HIV/AIDS and TB and other global health challenges and dedicates significant resources to advocacy, awareness campaigns and provision of social, economic, development and humanitarian actions in the field.

major 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.

Children need to have access to Isoniazid Preventive Therapy (IPT): 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 inexpensive and simple: a daily dose of a drug called isoniazid.

“Child-friendly” treatment formulations for TB and “child-friendly” treatment formulations for TB/HIV co-infection in children are lacking: Very few paediatric formulations of TB drugs have been developed and those that do exist are not widely available. Currently there are no TB Fixed Dose Combinations (FDC) available for the recommended treatment regimen. This means that children are required to take multiple tablets, or breaking tablets to get the right dose, running the risk of over- or under-dosing a child. It is planned that a “child friendly”, FDC dispersible will be released in October/November 2015.

Health and social programmes that address Childhood TB with HIV/AIDS care, nutrition, immunization, child and maternal health should be integrated: National public health authorities, as well as faith-based and other civil society health care providers and advocates seeking to prevent deaths from TB among children living with HIV must exercise bold political leadership to integrate health services for women and children at every level of society and must do so 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 and immunization services will prevent millions of unnecessary deaths among pregnant women and their children.

TB is preventable and curable. Help us to spread this news!

What I TB? How Is It Treated?

Tuberculosis (TB) is caused by a bacillus (“germ” or disease agent) called *Mycobacterium tuberculosis* that mostly lodge in the lungs but also can affect other organs of the body. Tuberculosis is curable and preventable. TB is spread from person to person through the air. When people with lung TB cough, sneeze or spit, they propel the TB bacilli into the air. A person needs to inhale only a few of these “germs” to become infected.

About one-third of the world’s population has latent TB, which means people have been infected by TB bacteria but are not (yet) ill with disease and cannot transmit the disease. People infected with TB bacteria have a lifetime risk of 10% to develop active TB illness. However persons with weakened (“compromised”) immune systems, including people living with HIV, malnutrition or diabetes, or people who use tobacco, have a much higher risk of becoming sick with TB.

When a person develops active TB disease, the symptoms (cough, fever, night sweats, weight loss, etc.) may be mild for many months. This can lead to delays in seeking care, and results in transmission of the bacteria to others. People with active TB disease can infect as many as 10-15 other people during the course of a single year, all due to close contact. Without proper treatment, up to two thirds of people ill with TB will die.

Since 2000, more than 37 million lives have been saved through effective diagnosis and treatment. Active, drug-sensitive TB disease is treated with a standard 6-month course of four TB (“antimicrobial”) medicines that are dispensed together with information, supervision and support to the patient by a health worker or trained volunteer. The vast majority of persons living with TB can be cured when medicines are provided and taken properly.

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**Norah**

Ms. Danielle Vella
AJAN Communications

In this issue of the HAART for Children Newsletter, we have the privilege to share the testimony of Norah, an HIV-positive mum, who got cured from TB with the support of Uzima programme for people living with HIV run by the Jesuit parish of St Joseph the Worker in Kangemi, a very poor settlement on the outskirts of Nairobi. Danielle Vella, from AJAN, the African Jesuit AIDS Network, collected this moving testimony, which also will appear in the March 2015 issue of AJANews!

“It was back in 2008. I was coughing so much and I was tested for TB at hospital and found to be positive. I was told TB patients should have an HIV test too and I accepted because I was suffering so much, TB eats you. It wasn’t easy. It was tough because I was taking TB and antiretroviral treatment at the same time. I was working, I had no strength, I was struggling because I had to provide for my children. Then I became so weak my boss told me to go home and rest. So there I was, jobless, children in the house, with HIV and TB. I have five children and I’m a single mum.

What helped me very much was that I joined a support group and we were introduced to a food program. We were given a monthly food basket. By then, I had nearly finished the six-month TB treatment but I made a mistake in the last week and did not take the medication well. So, after three months, the TB came back and was much tougher, it weakened me so much for a whole year, not least because I had to take the TB treatment and ARVs together. My CD4 count dropped and I lost weight. But this time I finished the TB treatment: injections and pills.

Meanwhile, I had transferred to another clinic because I wanted to move to be closer to my sister, who was helping me with cooking and other household chores.
I started going to another support group where I attended training too.

This was a new beginning because I learned a lot of things. I lacked knowledge before, I did not know much about TB and HIV, but after going for training, I picked up information, I regained weight, my CD4 count rose and I became a healthy person again. I could start caring for my family.

The training helped me to accept that I am HIV-positive because before I used to deny it: I am taking ARVs but this can’t be happening to me. I improved on adherence, taking medication on time and never missing appointments, and good nutrition, because I learned that nutrition goes with ARVs, it will help my body build more cells, while ARVs will help my CD4 go up and stop multiplication of virus.

I also understood how important it was to disclose my HIV status to those close to me, because I may be sick or bedridden, and they would not know what to do, even which clinic I go to. At first I thought it would be hard to tell my children but I did and it has helped, because they do so much at home, they don’t just leave mum to cook, giving me time to rest.

After some time, I had to relocate again and I came to Kangemi. Someone told me there was a support group at the parish of St Joseph, I went around looking for it and I was given appointments to visit the counsellor of Uzima, the parish. Again my life changed. I came for support group meetings, I found so many other mothers around, and I felt I was not alone. Before I had thought I was the only one and I was seeing only death, not life. But here I felt encouraged, our counsellors encouraged us so much and from that moment onwards, I am seeing only hope. People outside don’t always understand us but we understand each other and help each other go on with life.

Sometimes I find daily work and when I have no jobs, I make my baskets and necklaces here [at Uzima] and I sell them at the market, and they have helped me to continue with life. I pray those who support us to go on and God will bless us.

The Jesuit parish of St Joseph the Worker in Kangemi, a very poor settlement on the outskirts of Nairobi, runs the Uzima program for people living with HIV. Uzima has 112 clients, who benefit from: material assistance, including nutritional support for those who need; home-based care; individual and group counselling with several support groups; educational support for orphans and vulnerable children; and backing for income-generating activities, namely modest vending concerns, poultry-keeping, tie and dye, soap making, bead making, planting crops and micro-credit.

One Uzima initiative is a self-help group called Hope of Life; the members of this micro-credit union support each other economically, socially, emotionally and spiritually. Free medical assistance is provided, together with transport to hospital for patients and relatives. Uzima has Friends of Life, who are trained in basic nursing care and, under the supervision of a nurse from the parish dispensary, visit beneficiaries at home. In response to felt need, Uzima has employed a fulltime social worker to conduct regular home visits and liaise with the counselors.

1 www.ajanweb.org
Photo: Norah and her family. Photo credit: Darrin Zammit Lupi/AJAN
In 2012, Caritas Brody (L'viv region) together with the Brody District Social Services Centre for Families, Children and Youth held a series of events to inform the public about tuberculosis. “Tuberculosis is much talked about in the press and on television but young people know very little about it,” said the medical personnel and other employees of this local Caritas organization. For this reason, they organized a comprehensive seminar on TB for the adolescent clients of “the One Hundred Talents studio”, which is a component of a programme sponsored for children whose parents have migrated to find employment opportunities outside the country.

The event was held in conjunction with World TB Day, 24 March, which coincides with the day, in 1882, when the German physician, Dr. Robert Koch, presented his discovery of the bacteria that causes TB. During the L’viv event, a number of informative, practical and creative activities were held. The film “Microscopic Killer” helped the young people understand the issue. Subsequently, the participants watched a performance by a group known as ‘What do We Know about TB?’ Performers. The adolescent participants expressed appreciation for the opportunity to apply their knowledge to suggest practical steps to prevent TB infection or to suggest that someone seek further check-up or treatment. Children participated in the programme by distributing informational booklets and answering questions posed by passersby. The event was closed with an art contest, entitled “Faces of TB”. The winners happily displayed their artwork.

In 2013, Catholic Relief Services, one of the member organizations of Caritas Internationalis from North America, received a $9.2 million Grant from the Global Fund to Fight AIDS, TB, and Malaria, for a 2-Year Project to address Tuberculosis in Mali.

The nationwide TB project in Mali relies on community volunteers who are trained in detecting the disease and making sure people adhere to their treatment regimen. Often referred to as Directly Observed Treatment, Short course, or DOTS, this strategy requires a healthcare professional or trained volunteer to watch patients swallow each dose on a daily basis.

“Tuberculosis is a preventable and curable disease if detected and treated in its early stages,” said Dr. Elena McEwan, CRS’ Senior Health Technical Adviser. “The cost of treating a patient with TB can be as low as $10 if the person adheres to the drug regimen for 6 months. If that regimen is interrupted, there is a greater risk of becoming drug-resistant, dramatically increasing treatment costs as well as the risk of death, and the potential to spread this drug-resistant strain to others.”

As TB is a highly stigmatized disease in many countries, the initiative also focuses on raising awareness and educating people about its spread and prevention. CRS trains community and religious leaders and people who have been cured of the disease to disseminate messages on the importance of detection and care. Evidence has shown that community collaboration has the potential to significantly increase detection and cure rates.

Additionally, CRS contributes toward strengthening the national health system’s ability to diagnose TB, especially in children, by providing newer, more effective equipment and training laboratory staff in the biological diagnosis of new cases.


Contributors:

Msgr. Robert J. VITILLO
Ms. Danielle VELLA – AJAN Communications
Caritas Ukraine
CRS Mali
Ms. Francesca MERICO
Mr. Stefano NOBILE

Edited by:

Msgr. Robert J. VITILLO
Ms. Francesca MERICO

For further information on the HAART for Children Campaign & feedback, please contact:

Msgr. Robert J. VITILLO
Special Advisor on HIV/AIDS and Health
Caritas Internationalis Delegation in Geneva

Phone: +41 22 734 40 05/07
Fax: +41 22 734 40 06
Email: infocaritas@caritas-internationalis.com