



Tuberculosis Survival Project Autumn 2008 Newsletter

TBSP Launches New Award to Recognize TB Advocacy Efforts

The Tuberculosis Survival Project (TBSP) is pleased to announce the launch of the Tuberculosis Survival Prize. An annual award, supported by a grant from Eli Lilly and Company, the prize will recognize innovation in TB/MDR-TB advocacy and social mobilization. The award winner will receive a certificate and \$2000 to scale up and/or replicate advocacy efforts. The winner and the two runners up (who will also receive certificates) will be profiled on the TBSP website. The deadline to enter for the prize is Friday 19th September 2008. No submissions can be considered after that date. All applications need to be written in English.



Background

Tuberculosis continues to be a global emergency. The World Health Organization (WHO) has reported more than 9 million new cases of TB, and approximately 1.7 million deaths from the disease in 2006, the most recent year for which data are available. In addition, there nearly half a million new cases of multidrug-resistant TB each year. The WHO estimates that there are more than 14 million people living with TB. Of these, some 700,000 are also living with HIV/AIDS.

Such statistics are difficult to imagine, and the tragedy is that 5,000 die every day because of this curable disease. Those who suffer and die are mothers, fathers, sons and daughters, grandparents, friends and partners. Each of them lost their life sadly and needlessly to the deadly TB pandemic.

Over the past few years the importance and urgency to involve HIV/TB, TB/MDR-TB affected communities in the fight against TB has been recognised. Everyone has a role to play in this battle. Many HIV/TB, TB/MDR-TB advocates and activists, and the role that they play, however, goes unrecognised. The Tuberculosis Survival Prize is being launched by the Tuberculosis Survival Project to reward the innovative work of these unsung heroes and heroines and to make a contribution towards those efforts.

Who is eligible to enter?

Individuals, groups or NGOs working in the field of HIV/TB, TB/MDR-TB are all eligible to enter the contest for the Tuberculosis Survival Prize. Applications from people directly affected by TB/MDR-TB are actively encouraged.

How to enter?

To apply for the Tuberculosis Survival Prize, applicants should complete the prize entry form (please see the TBSP website for details www.tbsurvivalproject.org or contact Paul Thorn at paulthornlondon@hotmail.com for an application form). Applicants will also need to provide a photograph of themselves.

- 1) Applicants should describe in 700-1000 words, what they as an individual, group, or NGO working in the field of HIV/TB or TB MDR-TB have been doing over the past two years to develop

- and implement projects and programs that stimulate social mobilisation around TB/MDR-TB, and/or grassroots activities that inform, empower and enable individuals with TB/MDR-TB to advocate for themselves, and/or have created patient led models that ensure greater support of people undergoing TB/MDR-TB treatment to improve adherence.
- 2) Applicants should describe in 700-1000 words how they will use the prize money to scale up or replicate advocacy efforts if they are the prize winner.

Judging the winner

The applications will be judged by an invited panel representative of a variety of sections of the global TB community.

Prize Presentation

The prize will be presented to the winner in connection with the International Union of Tuberculosis and Lung Disease in Paris, 16th-20th October 2008 or, in the absence of the award winner, by someone else on his/her behalf.

Other

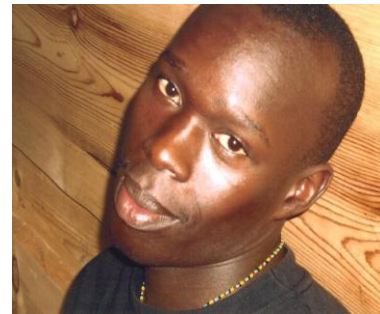
Please send applications via the Tuberculosis Survival Project website, www.tbsurvivalproject.org, or by email to Paul Thorn at paulthornlondon@hotmail.com by Friday 19th September 2008.

Disclaimer

The judging panel's decision is final. By applying for the prize, applicants give their permission for the TBSP to post information they submit on their applications to the TBSP website. This information will be used to inform others about applicants' projects and initiatives. By applying, applicants also give their permission for any photographs they submit to be used in any publicity related to the prize, the Tuberculosis Survival project website, and any other newsletters or printed material to inform the public about TBSP work in conjunction with the Lilly MDR-TB Partnership.

TBSP Featured in New Documentary

TBSP has been involved with a documentary by Benjamin Ocaya, a former MDR-TB patient himself. The documentary, with the current working title of "The Silent Killer", is about MDR-TB and is aimed at patients, but Benjamin says should have a wider appeal to the general public. The film will be about 30 minutes long and is partly funded by LHL (Norwegian Heart and Lung Foundation) and the Norwegian Red Cross. The film will be available to view on the TBSP website this autumn.



Spanish Version of TB Tips Available

A Spanish translation of TBSP's popular TB Tips booklet called "La Tuberculosis – Informacion Y Consejos Para Vencer La Enfermedad" is now available on the TBSP website. Download the PDF of the booklet for free at: <http://www.tbsurvivalproject.org/handbook.html>. A French translation of the booklet and Bosnian Herzegovina version will be available very shortly, Hindi version still in progress!

Patient Focus: Keep a diary - EXPRESS YOURSELF!!



Self-expression is very important when you are unwell with an illness such as TB. You will possibly feel a whole myriad of emotions. From anger to fear and everything in between, that said you are likely to have lighter times that could even be humorous. All of those emotions are valid and you will find it beneficial to explore them.

So why write? Many people in history who had TB were inspired to write about it. You will find that literature is scattered with the names of great writers and artists who created their best works whilst they were unwell. There was even a school of thought that to be creative one had to be 'consumptive'. This word was commonly used to describe someone who had TB a long time ago. The suffering writer with his quill in hand is a popular image of TB historically.

Sometimes when people have an illness such as TB they feel bad about themselves. This is called internalized stigma. So what is internalized stigma? It is when we take the historical perception of a disease and then mix it with society's fear of infection with disease. Tuberculosis in particular holds an unenviable position in the collective mind of society. When we as individuals then turn this thinking in on ourselves it can leave us feeling dirty and ashamed about the illness we have. The fact is that Tuberculosis and Multidrug-resistant tuberculosis is an infection that can be cured with the right treatment like a great many other infections. However taking TB treatment can take a long time, 6-9 months for fully drug-sensitive TB and sometimes two years or more for Multidrug-resistant tuberculosis. Many people find it difficult to take TB treatment for such a long time and sometimes they become chaotic about their treatment, meaning that miss doses, or they don't take the medication at all. This is very dangerous. Not only to the person who has TB, but also to other people around them. This is because when doses are missed, or an individual with TB stops taking the medication the TB can come back and the drugs usually used to treat the disease will not work as well, or even over time, not at all. This is sad, because TB is a curable illness. However, when people can't adhere to treatment as instructed by the TB doctor or nurse if there is no clinical intervention to help an individual stay on course with the treatment regimen, some people do unfortunately die. This need not happen.

Keeping a diary and writing about having TB will help you to take your TB treatment. It is your responsibility first and foremost for yourself to keep taking your TB medication, and secondly, but equally important for others around you who might be at risk at getting TB from you if you don't. The reality is that this responsibility to take such a lot of tablets is daunting, especially when people with TB have to take medication to cure the illness for such a long time. Keeping a diary will encourage you to stay on course with your treatment, as well as giving you the opportunity to express yourself and your feelings during the TB treatment journey.

Do you want to share your experience of having TB/MDR-TB with others?

The Tuberculosis Survival Project would like to hear from you. If you would like to share your experience with others then why not write about your own TB story. Take a look at the READ STORIES section of the project website www.tbsurvivalproject.org if you need to get an idea of what other people have done. Stories need to be no more than 1000 words long and you must give permission for your story to be included on the website.

Recently diagnosed with TB/MDR-TB?

If you have recently been diagnosed with TB/MDR-TB then you may find the following resources available on the TBSP website www.tbsurvivalproject.org useful.

Overcoming Tuberculosis is a 32 page booklet that you can download for FREE as a PDF. This booklet is applicable to anyone who has TB/MDR-TB. It has been written to help the patient understand what TB/MDR-TB is; how you get the disease; how it is diagnosed; how it is treated and cured. This will help the patient to understand why adherence to treatment is so important. The booklet aims to guide the patient through the TB treatment journey and includes many helpful suggestions along the way. You will find the booklet at: <http://www.tbsurvivalproject.org/handbook.html>

You may also find the pre-made TB treatment chart useful. You will find it at http://www.tbsurvivalproject.org/archive/archive_top.html. Just print one off for each month that you are on treatment and write in the names of the medicines that you are taking. Place your medication and TB treatment chart somewhere you will see them. Perhaps near by where you make your morning drink is a good place? Tick off the boxes on the chart when you take your medication. Remember: If you are having problems taking your TB medication always speak to your health care provider about it. They may be able to suggest other ways to take your medication that are more suitable for you. TB /MDR-TB is curable but only when there is access to treatment and you take your medication as prescribed.

Did somebody say something....?

“As the hours passed, and the clocks in the village sounded midnight, one, then two o’clock, and sleep receded before him like the horizon on a swimmer, his thoughts became progressively less coherent. He was not always certain of his location or circumstances, and could only substitute fresh fantasies of time and place for those which his intelligence managed to reject. Sometimes a sudden access of pain in his chest would restore him to momentary lucidity, and he would reflect with dismay on what his state must be the following day as a consequence of so troubled a night.”

A.E. Ellis – The Rack

Do you have something to say?

If you have a story or something else that you want to share with others, then drop us a line via the project website. Alternatively you can email paulthornlondon@hotmail.com.

The Tuberculosis Survival Project is funded by an unrestricted educational grant from Eli Lilly and Company and is a member of the Lilly MDR-TB Partnership.