



New Leadership at the Stop TB Partnership - Europe

On 27th June 2007 the interim Executive Committee of the Stop TB Partnership for Europe met in Riga, Latvia. The reason for the meeting was to discuss the new action plan with the wider Partnership and also to elect the next Executive Committee.

The Partnership was launched in Geneva in October 2006. It is different to the 'global' Stop TB Partnership as its focus is only on 53 countries across Western and Eastern Europe as well as Central Asian countries. The interim Executive Committee's first mission, since the Partnership started, was to lay the foundations for future work. It is now the role of the newly elected Executive Committee to try to mobilize the resources needed to carry out the action plan.

Mick Matthews of the Global Fund was elected Chair of the new Executive Committee and will be in post for two years. Also now at least a third of those on the board are Russian speaking. Unfortunately affected community interest in the Stop TB Partnership for Europe has been negligible. There has been much discussion around the language barriers that exist which makes it difficult for affected community representatives to participate if their first language is not English. However, it appears that we have now found a way forward to provide translation facilities into Russian, making representation from Eastern Europe viable. It is hoped that affected communities will now get behind the Partnership and play a key role in the decision making process.

Paul Thorn of TBSP, with the mandate of the ECUO (East European and Central Asian Union of HIV Organizations) remains in post as an interim measure representing affected communities. Paul said; "I really hope that other affected community representatives will get involved now. My primary role here is to facilitate the inclusion of Eastern European representation irrespective of their ability to speak English. I hope we can get on with an election process that is favourable to everyone concerned sooner rather than later. I can't stress how important it is that we have Russian speaking voices representing Eastern Europe."

TBSP website to get an overhaul

The TBSP website has been growing with leaps and bounds over the past few months. It is currently getting an overhaul, and a new look, to make the website easier to navigate. Watch this space www.tbsurvivalproject.org!

Internalized Stigma First, Patient Empowerment Later

“... I want to try and escape from my terrible illness. That again you can't be expected to understand. You think I am like other people – I mean normal. I'm not. I don't know which is the ill me and which is the well me. I am simply one pretence after another. Only now I recognize it...”

(From The Letters of Katherine Mansfield written less than three months before her death due to TB on the 9th January 1923)

The internalized stigma of having TB/MDR-TB is difficult for many to cope with. It is one, if not the hardest aspect of having the disease. So what is internalized stigma? It stems from the historical perceptions of TB we hold, and our own personal prejudices about infectious diseases as a society. We then turn these feelings on ourselves. People with TB/MDR-TB can feel dirty, lonely and marginalized, even before we tell anyone else we have the disease! Indeed it can make us question the very essence of 'who' we are, like the late, great writer Katherine Mansfield said; “which is the ill me and which is the well me”? For many it might lead to the answer; “I simply don't know anymore”.

So how can we expect people who have/ or have had TB/MDR-TB to get involved with affected community activities and 'show solidarity with others' when something so fundamental stops many at such a personal intrinsic level in the first place?

Before anyone who has had TB/MDR-TB can become 'empowered', and/or become an effective advocate and represent affected communities, there is a need as an individual, to address one's own inner feelings about having the disease first. Having TB/MDR-TB can feel like living with the worst imaginable housemate who just won't go away, not only in our bodies, but also in our minds, and at a very core level.

It is not a 'moral responsibility' for those who have, or have had TB/MDR-TB to become activists, advocates, or simply 'show solidarity with others'. There is the right to privacy and the right of choice to consider. These rights are enshrined in human rights law. Many who have, or have had TB/MDR-TB don't want to get involved in activism, and nor should they be pressured to do so, if they don't want to. Those who are already “out” about having, or having had TB/MDR-TB, realise that first and foremost it is often a very personal internal battle before they can even think about others.

An Individual's own internalized stigma around having the disease needs to be addressed before anything else. What we can do as existing activists and advocates is to offer the hand of friendship, to share our own experience of the disease through telling our stories, and present the opportunity to get involved. Only when internalized stigma is addressed can people with TB/MDR-TB be truly empowered.

Seonai's World

TBSP wants to welcome Seonai Chongrak to the team. Seonai, who has recently been discharged from hospital for TB treatment will be writing a regular column for the website. She believes that she may be on treatment for the next year and the column for TBSP will document her experiences.

Seonai, originally from Scotland, lived in Thailand for several years where she believes she may have become infected. She has a media background and is an excellent writer. TBSP believes Seonai's input will be illuminating, sensitive, and humorous. We had a good laugh over the telephone about her having lipstick on under her face mask as she wandered about, even though she knew no one else could see it. We very much look forward to publishing her first contribution in the coming month.

Translation Update

In the last newsletter we announced that the TBSP website was being translated into French. The language issue, and how to be more inclusive of those who's native language isn't English, is becoming increasingly important. If TB/MDR-TB affected communities are to be effective in representing themselves, then the translation issue has to be addressed. Admittedly there are logistical and financial implications of providing translation for more inclusive affected community representation. However, more positive moves need to be made than are currently being done to achieve this. TBSP, in the spirit of being more inclusive has also set the wheels in motion for a Russian translation. It is hoped that both translations of the website will be online by the beginning of August 2007. PS: we haven't forgotten about the newsletter – a French translation of that also coming soon! Give us a little more time to get it also translated into Russian!

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.

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