



## Report of TB Europe Coalition Visit to Belarus

November 2014

### Introduction

From 20<sup>th</sup> – 24<sup>th</sup> November 2014, three members of TB Europe Coalition's (TBEC) Steering Committee - Paul Sommerfeld ([TB Alert](#)), Nonna Turusbekova ([TBC Consult](#)), and Oxana Rucsineanu (*SMIT:TB Patient Organisation, Moldova*) – met with several individuals and organisations in Minsk, Belarus, interested in TB. In addition to these meetings, the team participated in a two-day Conference “Community role in the life of TB affected people through Global Fund (GF) processes”. The visit to Minsk was facilitated by Defeat TB Together (DTT). DTT is a republic-wide NGO, formed mostly of TB patients, doctors and nurses, starting to work on advocacy, care and support.

The visit to Belarus was part of a series of field visits that have been undertaken by members of TBEC. These visits have been to countries in the WHO European Region with a high burden of multidrug-resistant TB. To date TBEC has visited Moldova, Ukraine, Romania, Bulgaria, Latvia, Estonia, Lithuania, Georgia, Azerbaijan, Armenia and now Belarus. This series of visits is made possible by a grant from Eli Lilly and Co; and the visit to Belarus was also partially assisted by financial support from a GIZ grant to Alliance Ukraine/TB Europe Coalition. The main objectives of the TBEC visit to Belarus, [as with previous country visits](#), were to:

- Understand in greater detail the challenges for civil society organisations working on TB or related areas (including the financing of TB information giving and the broader local NGO landscape);
- To further involve Belarus NGOs in future TBEC activities;
- Explore potential opportunities for donors to support local NGOs in TB work.
- Co-facilitate a two-day workshop (or Conference) “Community role in the life of TB affected people through GF processes”

### Meetings

During the first two days in Minsk, TBEC met with WHO Belarus Office, the chief of the national TB Dispensary, Belarus Red Cross and the representatives of BelantiSpid. The following part of this report summarises some of the most relevant discussions had with these stakeholders.

- ***National TB Dispensary***

TBEC met with the Director of the national TB Dispensary. During this meeting, the official TB data was reviewed: Belarus has a high burden of Drug Resistant (DR)-TB, but with all the effort made, Belarus NTP has succeeded over the past ten years in reducing by 30 % the incidence of TB and in halving mortality due to TB. The success rate for in-patient treatment is 70 % and 54% for ambulatory treatment in its current form. In this context, the expected role of the republic-wide Civil Society Organisation DEFEAT TB TOGETHER (DTT) was stated. DTT is seen as a good mechanism contributing to patient adherence, as 54 out the 70 members of this NGO are former patients. DTT is expected to contribute to psychosocial support for patients and interventions with defaulters and difficult patients.

- ***Belarus Red Cross***

The Belarus Red Cross (BRC) is one of two international NGOs playing a substantial role in TB care and control in Belarus. They are providing psychosocial support to homeless patients and to detainees. There are 8 offices of RC in Belarus. They trained 250 volunteers to provide support to 500 MDR-TB patients. With Government support, they established a HOTLINE in order to facilitate the work with TB patients. The BRC interventions in TB refer to social support (nutrition, clothes) and advocacy for reintegration in work and obtaining a disability benefit during the treatment period. Before starting work with a patient, BRC obtains patient agreement for involvement in their personal life. Interventions with homeless patients are based on screening this group of people and offering motivational packages to encourage them to come after screening results. RC also trains directors of large factories in TB literacy and the necessity of social responsibility toward TB diagnosed employees. Belarus Red Cross includes a TB component in existing projects when the need arises. The conflict in Ukraine has led to more than 7000 Ukrainians coming as refugees to Belarus. This group of people is also screened for TB.

- ***World Health Organisation (WHO)***

The meeting with WHO highlighted their strong recommendation for moving to ambulatory treatment. There is an urgent necessity of finding good allies in implementing ambulatory care for TB patients. WHO talked about the project ongoing in Mogilev Oblast that is intended as an official assessment of ambulatory treatment. Although the project is not yet over it is already very clear that there are big advantages to reducing beds in TB hospitals and redirecting the money involved to supporting community work by nurses. Facilitating TB patient Directly Observed Treatment (DOT) within ambulatory care has very good results in increasing patient adherence. 1 US\$ is given to the nurse if the patient comes to take his treatment at the dispensary and 4 US\$ if the patient fails to show up and the nurse visits him at home to perform DOT.

- ***BelAntiSpid***

BelAntiSpid is a network of 17 NGOs working in HIV and managing significant interventions in most-at-risk populations (youth, detainees, women, PLHV, MSM, S, PHID etc).

Beyond particular concerns discussed, this meeting was especially valuable for the fact that BelAntiSpid representatives reflected on TB as a very serious problem among individuals who are HIV positive; and that TB continues to be considered a purely medical issue in Belarus. They openly talked about their willingness to be involved in TB activities.

- ***Defeat TB Together (DTT)***

The NGO “Defeat Tuberculosis Together” is a good initiative, relatively young and impressive, compared to similar groups in other countries, for being formed mostly of former patients (54 individuals, making up 77% of the membership). There is need of capacity building to help them become an effective player in Belarus TB control.

Lack of financial support for implementing TB action, compounded by state bureaucracy delays in registering an international grant agreement, is difficult for them.

Still with a lot of voluntary effort and financial support from UNDP (the sub recipient of GF), DTT managed to set up the Conference we came for, with a presence of almost 60 people: DTT members, BelAntiSpid representatives, WHO, BRC, NTP, UNDP, GF, and MSF.

***Conference “Community role in the life of TB affected people through GF processes”***

In addition to the meetings, we participated in this two-day conference. The 1<sup>st</sup> day constituted mostly plenary sessions with various presentations of national experience in TB control (BRC), international experiences (Britain and Moldova), the work in TB of international coalitions (TBEC and GCTA), NTP Concept Note presentation and a presentation by the GF Portfolio Manager about their New Funding Model and the country dialogue process. .

The 2<sup>nd</sup> day was a participatory workshop for the members of DTT and other local civil society (CS) representatives, facilitated by Nonna Turusbekova, directed at drawing out new ideas of from Belarus civil society that they would like to see reflected in the concept note that is soon to be prepared for the GF. It was a country dialogue in itself, focused on consolidating ideas as clear and defined recommendations for involving CS in TB Control and offering them a role in the country dialogue and writing of the Concept Note. A clear step-by-step plan was developed for this involvement. A working group, consisting of members of DTT and some civil society members of the Belarusian Country Coordinating Mechanism, was created to press for inclusion of the recommendations in the country Concept Note.

Group work during the workshop let participants explore the main challenges for civil society involvement in TB control as well as valuable interventions in key affected populations (KAP). It was good to see all participants work effectively together and there was a clear potential for these organisations to play an important role in TB support and advocacy in the future. A detailed report of the workshop in Russian language is in Annex 1.

- **UNDP**

During the workshop we heard about UNDP's amazing experience in initiating 'Patient Schools' in TB Dispensaries. They consist of a curricula of 5 lessons/modules directed at improving awareness and TB literacy between TB patients. Knowledge and information about TB is given to groups of 5-6 patients with a view to increasing adherence. It appears to be an absolutely great mechanism for training patients but their effectiveness should still be evaluated.

- **Medicins Sans Frontières (MSF)**

MSF (along with BRC) is another international NGO which is just setting up a project to help the Belarus NTP drastically improve adherence and completion rates among MDR-TB patients. One of our team stayed an extra day and helped facilitate a meeting between MSF and DTT. Both sides explained their roles and possibilities for action. MSF would like DTT to help arrange for 'buddy' support of MDR individual patients. They will make contact with DTT once their project is ready.

- **Comments regarding the Belarus country visit**

It was most encouraging to learn that incidence of TB in Belarus has been cut by a half over the past ten years. The counterpoint to this impressive progress, however, is that the country has some of the worst rates of extremely- and multi-drug resistant TB (X/MDR-TB) anywhere in the World. We were told of 700 XDR just this year, an incredibly high number.

This presents a great challenge and hopefully our comments below which relate only to our area of expertise, civil society engagement in TB action, will be helpful to all concerned with ensuring effective detection, treatment and care of individuals with TB in the country.

- There is interest and willingness by the NTP to make good use of civil society organisations in TB care but as yet the overriding approach remains focussed on the medical aspects of TB action and there is limited awareness of how to incorporate the social skills of civil society groups. The Mogilev Oblast pilot for home-based care would appear to be encouraging though we did not have the time on this occasion to visit it.
- *Defeat TB Together* (DTT) is a unique organisation for the very high proportion in its membership of individuals with personal experience of the disease, and for the number of doctors and nurses also involved. As such it is exceptionally well-placed to be an effective resource for community action on TB. There are few similar organisations in other countries and Belarus can be proud that in the very short time since its inception, DTT has managed to build a nation-wide network of active members.

It is in need, however, of support for capacity-building of its organisational policies and structures.

- It was also encouraging that *BelAntiSpid*, an HIV-focussed organisation, is evidently interested and wanting to broaden its activity to include work on TB. It understands that all too often it is TB that kills individuals who are HIV positive.

Together with DTT, these organisations represent a rich resource for enhancing the effectiveness of the NTP.

- Civil society organisations such as these are especially important in responding to X/MDR-TB. The long periods of treatment make social and personal support to individual patients absolutely essential. It is this that is under discussion between DTT and MSF.
- Funding is a problem. Foreign grants (Global Fund, Stop TB Partnership, etc) can be helpful initially but in the longer term it will be necessary for government to find ways to build into its health budgeting, funds with which to support work by civil society organisations.
- We learnt that forced treatment is commonly used. Experience and studies in other countries show that such policies are counter-productive and have the opposite effect to what is wanted. The intention of such programmes is to reduce transmission by ensuring compliance by individual patients. Often however, individuals with the disease, hearing of the compulsion, will disappear to avoid it. Not only does this mean interrupted treatment for the individual but the effect is to increase transmission.

Much more useful is to strengthen social support for patients on ambulatory care so that they are assisted to willingly complete treatment.

### **CONCLUSION**

The country visit and workshop were a good step in bringing all partners together to reflect on how civil society in Belarus could contribute to changing the situation in TB control. Even though national civil society organisations are new to TB and have not played a big role in TB control until now, the workshop created the foundation for a society platform willing to contribute to TB control in Belarus.

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13.01.2015

**Annex 1. Detailed recommendations for inclusion in Belarus Concept Note for submission to Global Fund**

**Предложения от гражданского общества для включения в страновую концептуальную заявку по ТБ**

Предлагаем включить деятельность по УСС (укрепление систем сообществ) в страновую концептуальную заявку по ТБ в виде отдельного модуля.

Мероприятия	Виды деятельности
<b>Укрепление потенциала, планирование и руководство развитием сообществ</b>	Техническая поддержка в управлении проектами.
	Стратегическое планирование и управление системами сообществ. Разработка систем для планирования мер на уровне сообществ.
	Укрепление потенциала организаций представляющих сообщества, в области стратегических инвестиций ресурсов, финансового планирования, финансового менеджмента, мобилизации ресурсов и планирования устойчивости.
	Разработка и внедрение системы управления, набора, мотивации и поддержки волонтеров.
	Укрепление потенциала в сфере лидерства, обеспечения мотивации, управления и надзора за деятельностью волонтеров.
	Развитие коммуникативных навыков (тренинги по ведению переговоров). Разработка и согласование программ по формированию и поддержанию приверженности к лечению, в том числе и при ко-инфекции.
	Развитие, управление и стандартизация (по мере возможности) схем вознаграждения волонтеров или создание других мер поощрения и источников дохода.
	Закупка инфраструктуры, а также других материалов и ресурсов, которые требуются организациям представляющим сообщества, для выполнения соответствующих функций.
	Финансирование текущих эксплуатационных расходов организаций.
	Разработка и распространение надлежащей практики оказания услуг на уровне сообществ, включая составление протоколов, надзор и управление.
Разработка планов отчетности и управления для руководителей организаций.	

	<p>Создание и финансирование центров поддержки населения на уровне сообществ, оказывающих различные услуги по предоставлению информации, юридической помощи, направлению и перенаправлению между специалистами и организациями здравоохранения, НПО, соцслужбами основных затронутых групп населения и сообществ в сфере ТБ.</p> <p>Выездные семинары для сотрудников и волонтеров.</p>
<p><b>Мониторинг подотчетности на уровне сообществ</b></p>	<p>Планирование, разработка и утверждение механизмов мониторинга и документирования на уровне сообществ.</p> <p>Мониторинг и разработка показателей оценки соблюдения законных прав потребителей услуг в сфере ТБ.</p>
	<p>Создание средств мониторинга (интернет сайт, телефон доверия, и др.).</p>
	<p>Публикация и распространение результатов мониторинга на уровне сообществ.</p>
	<p>Подготовка специалистов по мониторингу на уровне сообществ.</p>
	<p>Техническая поддержка и обучение</p>
<p><b>Информационно-разъяснительная деятельность в целях повышения социальной ответственности</b></p>	<p>Разработка и распространение информационно-разъяснительных материалов по ТБ (юридические вопросы, вопросы по снижению стигмы и дискриминации, современные методы лабораторной диагностики, адвокатирование закупки новых противотуберкулезных лекарственных средств).</p> <p>Осуществление информационно-разъяснительной деятельности (проведение встреч, кампаний, публичных информационно-разъяснительных мероприятий, и т.д.).</p> <p>Организация консультационных групп, сотрудничающих с медработниками и выступающих связующим звеном между врачом и пациентом. Организация обучающих семинаров с участием психологов ЦРБ, врачей-валеологов (ЗЦГЭ) и представителей НПО. Работа с пациентами и их семьями (выездные мероприятия на местах) по повышению уровня информированности.</p>
	<p>Организация комплекса мероприятий по повышению уровня информированности по вопросам инфекционного контроля профессиональных групп риска (милиция, первичная медицинская сеть, служащие социальных отделов и т.д.).</p>
<p><b>Социальная мобилизация, установление связей внутри сообществ, сотрудничество и координация</b></p>	<p>Создание и поддержка механизмов координации и совместного планирования в целях установления связей между представителями сообществ и связей между сообществами и другими заинтересованными сторонами на местном, национальном, региональном и международном уровнях.</p>

Создание и поддержка платформы для сообществ в сфере ТБ, ТБ/ВИЧ среди основных затронутых групп населения, для обеспечения эффективного представительства и информационно - разъяснительной работы на национальном уровне, а также для обмена опытом, и т.д.

Повышение информированности субъектов сообществ об их правах, предусмотренных обязательствами поставщиков услуг.



**Предложения в дополнение существующим модулям:**

**Группа 1 Лечение и профилактика ТБ**

- 1.Создание мультидисциплинарной команды с вовлечением госструктур и НПО.

**Группа 3 МЛУ - ТБ**

- 1.Наглядная позитивная информация по формированию толерантного отношения к людям, затронутым МЛУ-ТБ.
- 2.Создание функционирующей системы психосоциальной поддержки пациентов с МЛУ-ТБ.

**Группа 4 Укрепление систем здравоохранения и гражданского общества**

1. Организация комплекса мероприятий направленного на психологическую поддержку медицинских работников противотуберкулезных учреждений для предотвращения эмоционального выгорания.