Good Practice

Stop TB Partnership
Challenge Facility for Civil Society

Financial support to community initiatives for positive change
Meet Esther:
How grantees are helping to save lives in Rural Nigeria

Patrick Amah, director of the GRADE Foundation, shares Esther’s story:

“Ms. Esther Oji is a 38 year old woman living in rural Nigeria. Like so many other women in her area, she faces significant difficulties in accessing proper health care. Without nearby TB testing, Esther’s TB illness went undiagnosed and rapidly became life threatening. A village-based health worker trained by the GRADE Foundation on a CFCS grant discovered Esther at a point of near death. The trained health worker alerted the local National TB Programme (NTP) supervisor, who took Esther to be tested for TB at the nearest Microscopic Centre. She was immediately placed on treatment once diagnosis was confirmed.

Yet Esther still faces major challenges everyday. She has been abandoned by her loved ones and now lives alone in a dilapidated building. She finds it very difficult to secure sufficient amounts of food. This is all the more difficult for Esther, who requires proper nutrition along with her TB medicine. With little means of transportation or strength, she has difficulty ensuring a regular supply of drugs.

GRADE Foundation made arrangements with the local NTP supervisor to ensure a steady delivery of drugs to her. Esther also receives occasional food donations from kind neighbours.”

Esther is one of many whose TB could go undetected and unreported, resulting in the death of thousands in rural villages. A lack of awareness combined with poor access to testing and treatment is a deadly combination. Stigma is still attached to many of those in Esther’s position.

In combination with awareness campaigns organized by GRADE Foundation, Esther raises awareness in her community as living proof that TB is curable and treatment is available. These awareness efforts are saving lives. Esther’s story also highlights the need for grassroots organizations to join in the fight against TB.
The Stop TB Partnership’s Challenge Facility for Civil Society (CFCS) fights the spread of TB by providing support to community-based organizations performing activities that result in policy change and collaboration between civil society and health services. The CFCS has awarded 88 grants totaling more than US$ 1.5 million to recipients in 37 countries around the world.

CFCS grants target grass-roots civil society organizations that seek to shape policy at local levels and improve TB care by giving a voice to people living with TB and those involved in its prevention, treatment, and care. The grants awarded aim to strengthen the community response to TB by increasing awareness, reducing stigma and discrimination, increasing local capacity and enhancing relationships with local stakeholders.

CFCS grantees work everyday with communities struggling with poverty and difficult living conditions. We believe that by helping to address some of the social determinants the impact of the WHO Stop TB Strategy will be increased.

All grants awarded by CFCS focus on creating an environment that supports patients and people living in TB-affected communities to advocate for their right to health, seek health care services and, for TB in particular, to receive treatment.

The following document outlines a selection of good practice examples from the third round of CFCS grants. For a full list of grantees from rounds one through four, please visit our website at: www.stoptb.org/global/awards/cfcs/

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Successes in the field
An overview of this document

The Challenge Facility for Civil Society has awarded grants to over 80 civil society organizations engaged in advocacy, communications, and social mobilization. Their projects have resulted in phenomenal successes. These success stories are evidenced by five main outcomes which will be highlighted with real examples in the following pages:

**Effective Advocacy** - Creating change at the policy level has long lasting benefits for TB-affected communities. CFCS grantees help to shape local policies by advocating for TB to be placed on the political and social agenda of the local district or province.

**Capacity Building** - CFCS grantees have engaged in programmes that build capacity at the community level. Programmes focus on building skills, community ownership, and training to mobilize communities.

**Raising Awareness** - Using compelling messages and innovative strategies, CFCS grantees have raised awareness of TB in their respective areas of work around the world. Thousands of people have heard the message that we can Stop TB.

**Positive Health Outcomes** - All health related programmes are assessed on their direct impact on the health and wellbeing of the intended audience. CFCS grantees have produced amazing results in improving health and helping to save lives.

**Reducing Stigma through Education** - CFCS grantees recognize that much of the stigma TB patients confront on a daily basis is due to misunderstandings and fear. Projects aim to increase public knowledge about TB in order to reduce stigma.

The CFCS provides support to organizations in the hope that their programmes will be scaled up in the future. Often, organizations must demonstrate success at the local level before they can secure funding for larger projects; CFCS hopes to be the first of many steps for these organizations. By implementing programmes at the local level, grassroots organizations are laying a foundation for larger projects in the future. Several grantees, such as the Sorak Development Agency (Uganda) and the Mwanza AIDS Support Organization (Malawi), have effectively scaled up their projects by linking with TB global partners.

Moreover, Stop TB Partnership’s CFCS has been instrumental in engaging many new grassroots civil society organizations working on other health issues to join the fight against TB. We believe this is integral to creating a strong network of partner organizations. This document highlights several examples of organizations new to the fight against TB such as the Centre for Communication and Development (Bangladesh) and the Committee on Monitoring of Penal Reforms and Human Rights (Kazakhstan).

We aim to connect partners with similar and complementary interests to help stop TB. In addition to building a network of grantees and partner organizations, the Challenge Facility also helps to link grantees with national health systems and national stop TB partnerships.

The Challenge Facility for Civil Society hopes to repeat these successes by providing the financial and technical support to small organizations when and where they need it the most.
UKRAINE - ‘Ukrainians Against TB’ passionately advocated for the rights of TB patients. Following a thorough situational and policy analysis, the NGO advocated with representatives of the Government and the Verkhovna Rada (Public Health Committee) of Ukraine to discuss the poor access and treatment of TB patients in hospice care. Based on the results of their work, a number of proposals have been elaborated and discussed at the highest levels of government. Specifically, their policy efforts aim to introduce changes and amendments into Ukraine’s legislation on public health to ensure compliance with present-day requirements of international law.

Ukrainians Against TB also proposed draft amendments to the ‘Budget Code of Ukraine’ and to regulations concerning local self-governance and local state administrations. The proposed amendments are aimed at ensuring effective use of funds of the public health system at the regional and local levels and at ensuring palliative and hospice care provision for patients with TB in a terminal stage.

Ukrainians Against TB demonstrates a success story; their efforts have contributed to local and national government recognizing their role in the fight against TB.

COLOMBIA - Multi Drug Resistant TB (MDR-TB) patients in Buenaventura, Colombia are understandably worried. Health insurance companies that the government commissions to give TB care, are often reluctant to provide coverage for the full time required for MDR-TB treatment. As a result patients often interrupt treatment leading to further amplification of drug resistance. Patients turn to Asociación Vida Salud y Bienestar for legal support against their health insurance providers. This NGO supports them in preparing court cases to go to trial, and trains people from the community on TB so that they can accompany patients to legal appointments and court hearings. The trained leaders have guided and counselled on a daily basis about 120 patients with TB on how to properly approach the health institutions that serve them so they will comply to TB care standards.

The Asociación Vida Salud y Bienestar works with representatives of the National TB Control Program, Doctors of the World, German International Cooperation, Doctors Without Borders, and the municipal health secretariat - the main actors in the region - to discuss collaboration in future work to address TB patients’ needs in Buenaventura. Moreover, they have created strong ties and supported the Robert Koch Association, a TB patient association, with advocacy training, legal guidance, and political negotiation.
Building Capacity
A ground-up approach to Stopping TB

The Tanzania Public Health Initiative (TPHI) engaged in a CFCS funded project to help build the capacity of TB-affected communities, civil society organizations, and TB patients. Through TPHI-led workshops on advocacy, communications, and social mobilization, individuals and organizations gained the skills necessary to return to their communities and engage them in the fight against TB. Additionally, TPHI trained over a 120 persons in a human rights based approach to TB/HIV.

By working through traditional leaders within the communities, TPHI shared key messages focusing on TB control and prevention with families. Participating community groups also provided information to 350 families caring for TB patients to reduce stigma and discrimination and promote treatment adherence.

Recognizing the need to work with, rather than against local culture, 15 traditional healers and 30 community leaders were linked with TB community groups to promote mutual understanding and collaboration. Furthermore, engaging all care providers is a key strategy to increase case detection and cure rates. TB education helped promote a positive relationship between traditional healers and health facilities in order to help patients receive the treatment they need.

Finally, the TPHI created links between 120 TB/HIV patients through the formation of six TB patient support groups. In addition to providing patients with a platform to share their lived experiences, these community-run clubs increase local capacity to respond to the needs of those living with TB.

Effective and Sustainable Practice

The Mwanza AIDS Support Organization (MWASO) in Malawi engages in innovative and sustainable projects that continue to run well after grant funds have been used. For example, the ten TB patient clubs founded by MWASO sustain their activities by planting small gardens and selling the produce for a profit. TB clubs then use these profits for volunteer transportation, nutritional support, and re-investment in the gardens. This innovative approach results in lasting change for TB patients.
Raising Awareness

Spreading the message that we can STOP TB

Centre for Communication and Development, Bangladesh

The Centre for Communication and Development (CCD) is harnessing the power of mass media to raise awareness of tuberculosis. The CCD project undertook several activities to help increase the exposure of TB in national and regional news. Firstly, CCD has provided TB orientation sessions to nearly 500 journalists and reporters. These sessions were paired with fellowships for reporters to produce indepth reports on TB issues. Moreover, dialogues with TB representatives help reporters understand the human side of the equation. Journalists play a vital role in disseminating necessary data, information and messages on TB issues to the people of Bangladesh. By enhancing the knowledge, skills, and capacity of reporters to produce compelling TB-related stories, CCD is ensuring that the importance of TB in Bangladesh does not go unrecognized.

Salama SHIELD Foundation, Uganda

The Salama SHIELD Foundation demonstrated the commitment and thorough planning that will be needed to create a world free of TB. Over 100 communities were introduced to the project through massively attended community meetings where local volunteers were chosen to help share the message in each location. These volunteers were trained in counselling and referral setting up a community case referral system. Key Stop TB messages to reduce stigma, improve treatment adherence, and to search out early diagnosis were dispersed through hugely popular performances by theatre groups. Music, dance and drama interspersed with education by local volunteers. This programme helped double the case detection in 3 health facilities in Lyantonde, Uganda. Salama SHIELD Foundation has demonstrated that we can all make a difference.

Pastoralist Journalist Network, Kenya

Communities, driven by cultural beliefs and misunderstanding, evicted, chased and ostracized TB patients from their family homes on the grounds that they contracted the disease as a result of a curse. Ali Ahmed - a patient - said that he was chased from his remote village by his father and community after others noticed his audible cough and tired looking body. He was forced out of their village and began to walk; this being the only way for him to cover the great distance to access treatment. Ali is now among hundreds of patients who will soon be discharged after finishing their treatment period. While receiving treatment, a CFCS funded project educated patients to become agents of change in their communities by reversing common misunderstandings of the disease and patients. The project also worked in villages to reduce the stigma and discrimination directed towards TB patients.
Positive Health Outcomes
Making a difference in the lives of those affected by TB

Stop TB Bouaké, Côte d’Ivoire
Through a massive project targeting individuals, communities, and policy makers, over 900 TB patients have been detected and placed on treatment; a three fold increase in the local area compared to the same period the year before. Stop TB Bouaké provided much needed nutritional and financial support, as well as temporary accommodation during treatment to those individuals most in need. This, combined with advocacy to fund the local TB clinic, community events, and education for community volunteers and other NGOs has saved hundreds of lives.

Wote Youth Development Project, Kenya
“Brian is 20 years old and has just finished high school but now has been infected with TB and fallen ill. Lucky enough he is seronegative for HIV. Thanks to the grant, Brian will have a treatment supporter attached to him who will be trained on how to take care of him and make sure he takes his drugs regularly. Brian and others like him are grateful to the unseen donor (Challenge Facility). It’s my duty to make sure Brian and others don’t die of TB.” The organization had 155 patients under its care.

Committee on Monitoring of Penal Reforms and Human Rights, Kazakhstan
Poor living conditions and inadequate health services often results in a disproportionately high number of prisoners suffering from tuberculosis. The project targeted this vulnerable population by conducting mass awareness campaigns, tuberculosis and MDR-TB education sessions and screening. Additionally, counseling and treatment sessions were arranged for all prisoners living with TB. An efficient tracking system was established for those with active TB infection who were released from prison to ensure that they continued their treatment. This grantee played a major role in reducing TB and MDR-TB incidence in prisons in that region.

ORISADE, Cameroon
ORISADE trained leaders within the sex worker community. These leaders went on to educate and support other sex workers who otherwise might be hard to reach due to stigma and discrimination. The programme provided much needed financial support so that hundreds of sex workers were able to access consultation and screening services. Those who needed treatment were referred and taken to the local health centre where ORISADE had advocated for better quality treatment of sex workers. In addition, all of the participants undergoing treatment received much needed nutritional support.

Hope For Future Generation (HFFG), Ghana
This organization used a variety of approaches to increase the number of community members who are screened for TB. Regular sessions were held where community members could receive TB education, be screened and give sputum samples. Participation was enhanced by a communications campaign that included regular theatre performances and radio programmes to help spread their message. Additionally, HFFG not only engaged in advocacy with local decision makers, but also trained traditional leaders, staff, media personnel, and former TB patients in advocacy and communications. This has resulted in close to 1000 community members being screened for TB, including several hundred HIV-positive people. All of those who tested positive for TB are now receiving much needed treatment.
Reducing stigma through Education

The BABA Foundation based in Kenya has helped reduce the stigma of TB and HIV through awareness and education. The project aimed to address common misconceptions regarding TB/HIV co-infection while supporting those who had both diseases.

The BABA Foundation was able to reach hundreds of people with appropriate TB/HIV messages through TB support clubs, community meetings, and community TB ambassadors. Additionally, local decision makers participated in a sensitization meeting which resulted in widespread pledges to increase support for TB/HIV activities in their communities. These stakeholders also delivered a community driven petition card to the district health authorities advocating for better access to TB/HIV services.

The SORAK Development Agency in Uganda engaged in a ground up, participatory approach to help fight stigma through public health education. SORAK focused on sharing accurate messages regarding TB/HIV co-infection through a variety of platforms: Interactive radio talk shows, participatory theatre, parish meetings, and community meetings all helped to spread the word.

In a door to door survey conducted before their project began, programme staff established that the vast majority (80%) of respondents were not aware of many basic facts regarding TB and HIV co-infection. In an area of the world facing a high burden of both TB and HIV, this left just 20% who knew common prevention strategies, where to access care, or how the two infections interact.

Towards completion of the project, the same study participants were surveyed again. It was noted that the level of knowledge and disease awareness had increased from 20% to 60%. This will help change the health seeking behaviour in the community.
CFCS strives to be more than a grant giving mechanism. We believe in helping organizations to grow by providing links to funding sources, partners, training opportunities, and valuable materials. When grantees take advantage of these opportunities, the Challenge Facility becomes more than just a source of funding; it becomes the first of many steps upwards.

One such example is the SORAK Development Agency. While implementing a successful advocacy and communications programme, CFCS put the organization in touch with the Bristol-Myers Squibb Foundation. By following through on this opportunity, they were able to secure a $50,000 grant along with expert training in TB/HIV tracking, monitoring, and evaluation.

There are many more examples of CFCS grantees who excel after linking with partners. Integrated Development in Focus of Ghana received the 2009 Survival Prize* awarded by the Tuberculosis Survival Project which applauded their advocacy efforts and provided funds for them to further their excellent work. Both the GRADE Foundation and Wote Youth Development Project were invited to speak about their successes in the field at one of the Stop TB Partnership’s Sub-Working Group meetings in Berlin, Germany, in 2010.

MWASO serves as an exemplar in this regard. While implementing an extremely successful programme to raise awareness and establish TB clubs, the organization, assisted by CFCS, was successful in securing a seat in the United Nations General Assembly High Level Meeting on HIV/AIDS. MWASO was in New York to profile TB in discussions towards UN declarations on HIV/AIDS with other major players.

Stop TB Partnership’s Challenge Facility strives to go beyond the ordinary by offering funds, connections, and opportunities for organizational growth.

* http://www.tbsurvivalproject.org/prize/winners.html
TB can be prevented

“The Salama SHIELD Foundation strategy will involve different religious leaders among the volunteers it will train to spread TB prevention... and will work hand in hand with health workers to select and train community-based volunteers from 111 villages...”

New strategy to fight tuberculosis in Lyantonde

Michael J. Magula

A research project in Lyantonde District has come up with a 12-month strategy to fight tuberculosis (TB). Salama SHIELD Foundation (SSF), an HIV research project established in Lyantonde 13 years ago, has embarked on a strategy aimed at raising awareness of TB spreading fast among HIV/AIDS victims and the availability of TB treatment for people living with HIV.

“Emanac to address HIV/AIDS in Lyantonde” said Dr. Kenneth Magula adding that the strategy would address the prevalence of TB among those living with HIV/AIDS in the district.

“TB is one of the most common and deadliest diseases in the world today,” he said. “Uganda is the fifth of the World’s 20 most affected countries with TB in the world.”

The strategy will involve different religious leaders among the volunteers to train to spread TB prevention among communities. SSF will work hand in hand with health workers to select and train 111 community-based volunteers to select and train community-based volunteers from 111 villages.

Photo credits
