



BRINGING CIVIL SOCIETY TOGETHER
TO END THE TUBERCULOSIS EPIDEMIC
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Romanian
Angel Appeal

Grass-root community advocacy in Romania

Over 300 municipalities, one fifth of Romania

In October 2015, the Romanian Angel Appeal Foundation started one of its longest lasting advocacy activities from the past years: local meetings with municipalities all over Romania.

The objective: to persuade them to acknowledge their responsibility and take more effective action in providing support services for the people affected by Tuberculosis living in their communities. We learned from the beginning that we needed to add a



second objective: to increase the information and awareness level of people working in both local authorities and local and central public institutions.

In one and a half year, we organized over 30 meetings, in 7 counties and in Bucharest, and we passed our message on to over 300 local authorities. In geographical terms, our community advocacy covered a fifth of Romania.

"Tuberculosis is a long forgotten tale"

First surprise (that wasn't exactly a surprise): but for local doctors, nurses and community health workers, very few people understand the real public health threat that is Tuberculosis. The decision makers at community level don't have the basic knowledge about the disease or even know it still exists. Most of them remember Tuberculosis as a disease from the '60s when they had to boil the milk and patients were usually treated in sanatoriums with a combination of drugs and non-pharmaceutical "water, sun, and food". Those who know that Tuberculosis still exists widely regard it as a disease of the marginal: very poor people, alcoholics, people who very rarely come in contact with local decision makers, education services or even with health care providers.

Second surprise (endemic and somewhat expected): the local authorities are very little interested in community health. Rural and small urban communities lack medium and long term social and health strategies and even in large cities it's difficult to find a coherent, sustainable, long term strategy based on a proper needs assessment.

Third surprise (truly disappointing): some TB doctors and most of the family doctors are not happy with treating TB patients in ambulatory. They strongly believe that the patient should be hospitalized until cured and that the community is not ready to accept and support TB patients. Things like family, job, school, social group, personal comfort that shape one's existence lose significance. Treatment and hospitalization are seen as compulsory and low treatment adherence is linked more to the patient's ill will than to the lack of ambulatory support services.



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"The patient is the disease"

For most of the local decision makers, the TB patient is only one thing: a patient. Community integrated support is still a new and blurry concept. Many of the decision makers don't see how or why they should get involved since there is at least one family doctor in the community who is the sole responsible with providing health care services. Stereotyping and generalization don't help either: the TB patients are mostly "poor, uneducated, alcoholics, uncooperative". This view does not come from real life experiences but rather from what the decision makers imagine a TB patient is.

The patient is the disease therefore any other needs it might have are not relevant until it is cured.

"Use the force, Luke"

Luke is a fantasy character but good people can be found everywhere. Our job is to point them in the right direction and give them the information they lack.

We tell the decision makers to never forget that the TB patients are people and the human rights stand above all. Even if it might sound counterintuitive, in Romania, the TB patient has the right to refuse hospitalization and treatment. There must be support services available in the community to educate them on the dangers of Tuberculosis for them and their loved ones. Social services should provide both social and financial support at a time when the family income of a TB patient can drop by 30-40% due to the disease. It's never a good idea to threaten the patient with prison time or to involve the police to forcefully bring the patient to the hospital.



Community health workers are one of the most valuable resources that local decision makers can use to make sure that Tuberculosis doesn't become a problem in their community. The Ministry of Health provides the funds to pay the health workers, what we do is try to convince them that they are a good addition to the local administration team. The mayors together with the local councils are those who decide to hire health workers. Now there are almost 2.000 such workers in Romania but they cover less than half of the country. So this is one of the points that we insist upon in our meetings.

TB patients require financial and material support, especially in rural and small urban communities which are usually poor, lack employment opportunities and are up to 30 km from the TB dispensaries. The local councils can decide, within the limits of the legislation, to help the TB patients with funds for ancillary medication, transport to the TB dispensary or emergency financial aid for those who are newly diagnosed.

Going up one level, we remind them that keeping a community TB-free can be done by keeping a community informed and educated. They have the resources to mobilize the community leaders, formal or informal, and bring them together with TB doctors who



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can give them the most relevant information on TB. This information can be passed on to the members of the community.

End of part one

Our best meetings so far have been the noisy ones. We don't want people to politely agree with us, this usually means that they can't wait to go home. We like those meetings that last over two hours and that continue for at least 30 minutes on the hallways because it means that our message was heard.

Part two comes up next: by the end of March 2018 we shall go to 7 more counties. Another fifth of Romania. And we're more confident every day that our small steps will lead, one day, to a giant leap in making the local communities more service-friendly for the TB patients.

by Cristina Enache, Advocacy Officer, the Romanian Angel Appeal Foundation