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**38th Union World Conference on Lung Health
We're All in This Together: Community Involvement in TB and
MDR-TB Prevention and Care
November 10, 2007**

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GIULIANO GARGIONI, M.D.: Okay, as I briefly mentioned [inaudible] in a number of international [inaudible] just slightly before the launching of the new Stop TB strategy. A number of colleagues and experts were raising questions about committee participation. Mostly because, as you know very well, at least from the Declaration of [inaudible] in 1968, in 1978 there has been many attempts of involvement of community.

And in a way in this context a slightly different or very different approach is being followed. So, we have contacted a number of contrary views in order to shed some light on precisely the meaning of community involvement and perhaps to understand better what are the most successful or more successful approaches to involvement of communities.

These are bullets summarizing the new Stop TB Strategy. As you see there are a number of new challenges that were unknown some 20 years ago, and that have been constantly present in the work and the life of people affected by TB and by healthcare workers.

But you can see that particularly component four and five address the approach that might be used to tackle all of the other challenges. One may use a public/private partnership approach, for example, to address the challenge of MDR-TB, and one may very usefully use a community involvement approach to

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provide anti-TB treatment or to provide support to a person on anti-TB treatment.

While it's very helpful not to define important but rather to describe what effective involvement is, it is useful instead to define what a community is. And we are proposing just a working definition of community as a reality that consists of people leaning together in some form of social organization and cohesion.

It's made by the significant [inaudible] and social economic profile, but the important point is that there is a common belonging based on the fact the members share social, cultural, economic characteristics, as well as, common interests and values.

First conclusion we should draw is that the communities therefore, an extremely important social entity, which is placed between the individual and the family of this individual and higher forms of social organizations, for example, a local or a national government. So, in social justice literature an entity like this is defined as an intermediate social body.

What were the expectations including the community involvement in this Stop TB Strategy? First of all we have already ample evidence of a documented positive impact of community based TB control initiatives in many countries and of the social value of these initiatives. So, there are a number of studies about the effectiveness and cost effectiveness of

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interventions in which communities are involved and studies about the acceptability of these interventions, people affected by the disease, as well, as to the health workers.

But we should certainly take stock of the fact that the society and the civil society are not sufficiently actively engaged in the TB control planning and implementation and evaluation. And in countries that have taken seriously the challenge of involving communities, one may often observe problems in scaling up quickly now community based models and challenges in motivating all levels of what you could call a community based system, so, within the health system and also outside in the community.

About involvement, as I said, it may be more helpful to describe the features of a successful experience in which people are really actively involved. First of all people should be taken on board from the start. People should be involved from the outset of an initiative and know the stages of designing an intervention, of implementation, and of evaluation of TB control efforts, including the periodic reviews that will take stock of our progress.

Secondly, a very important point is that involving community and empowering the community is not simply the last step in the process of this de-centralization, especially if we think of the vertical process of the de-centralization.

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It's rather a horizontal process that goes beyond the boundaries of the health system to establish a partnership with the society. In order to do that, therefore, it is extremely important that there should be a clear definition of the roles and the responsibilities for all the partners involved.

Clearly communication and social mobilization play a key role and we know very well in the TB control community how communication and social mobilization have been for a long time somehow neglected. No way we actively a community without communicating effectively with the people we want to serve and with the people we want to establish a partnership. This is absolutely necessary.

And then another feature is the commitment of all partners to pool resources and follow the guidelines agreed upon. Last but not least, the point of motivation which is the key issue in terms of assisting ability of a community based intervention, motivation we saw is often solidly the rooted in personal and community values.

What are these values? These are things that come from interviews administered to people with TB, people with HIV infection or AIDS, and health staff. Community involvement places the dignity of this person at the very center of health services. This is the first and founding value.

This value is at the origin not only of rights, but also of responsibilities that the society affirms and accepts

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to make progress towards a common good which would benefit all of its members. Empowerment, therefore, of people is the fact that people recognize their rights and assume the responsibility for their own health. And this empowerment has at least two fundamental dimensions, solidarity and subsidiarity, and I would have to recall here my previous definition of community and intermediate social body.

Solidarity, we all know is a model responsibility to share needs and problems [inaudible] and to recognize and defend the dignity of each individual. We have seen in practice many times and people have reported that when solidarity is upheld stigma is reduced, discrimination is reduced. But then we have exactly those realities I mentioned before, the family, spontaneous groups, associations, all local realities to which people spontaneously give life.

The following presentations will provide a powerful example of that. And yet precisely this reality that enable people to achieve an effective personal and social growth. So, the principal of subsidiarity states, it's a principal well known in social justice, it states that the higher institution or level of the society should support and promote what a lesser form of socialization can do. And, therefore, government should recognize and support as part of the public system other actors that institutionally do not belong to the state, recognizing, therefore, a public function of private

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initiative. This means that all actors that are, as a matter of fact, providing care should be taken on board, and first of all the people who may be affected by the disease either in themselves or in their relatives and friends.

This is my final slide. Just to summarize the fact that we are therefore looking at, we have a vision of moving towards a partnership for health between government, formal healthcare providers, and the society and the community.

So, the involvement on individuals and communities contributing to the life of the society to which they belong is an essential condition for a subsidiary approach to the delivery of services. And the involvement in activities that contribute to the common good is their right and their responsibility for everyone.

Regardless of, of course, outcomes impact of these initiatives is very important, but we should not forget the fact that these kind of partnership with the society is a benefit, per say. There is a value in it that goes beyond the immediate operational return, because it strengthens all the partners and builds a social capital, which is extremely important not only for TB control, for HIV/Aids control, and for any health initiative or not only health initiative that one may think.

And finally these are interventions therefore, that are designed precisely at the level where problems occur. So, the

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people who are most affected are likely to give us, who provide technical solutions, the right answers on how to deliver this solution and how to deliver them effectively accessing possibly as many people as possible.

Now my colleague will continue highlighting briefly the main steps that in a way we have observed across very different experiences, steps that could occur in different initiatives of community involvement. [Applause]

LANA VELEBIT: The first step in the implementation process is setting up a task force with representation of all relevant partners to guide policy and implementation. Advocacy is key for building and maintaining political and financial commitment, insuring the buying of all stakeholders.

Communication in this process aims at carefully, should be carefully designed and aims at creating awareness about TB and available services. Situation analysis should be followed by, the situation analysis of TB delivery and a discussion also should take place on how the community can compliment the tuberculosis program capacity and it is key for the community to be represented in this process.

The next step is identifying interested partners on the ground, and discussing the role of each of the stakeholders involved and planning activities jointly. Creating [inaudible] should be avoided in areas where existing community initiatives

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are ongoing. Creating synergies with those existing community initiatives will ensure assisting ability of the initiative.

The model of involvement of communities in tuberculosis should be designed together with partners and the communities and issues to be addressed include defining clearly the role and responsibility of each partner, ensuring regular contact between the health services and the community, encouraging the referral symptomatic persons, early referral of symptomatic persons, ensuring optimal care and the [inaudible] to treatment, addressing motivation within community involvement, addressing differences in the model in urban versus rural settings, and ensuring adequate recording and reporting of community contribution.

The points to particularly keep in mind in capacity to building ensure securing funds to train facilitators who will promote community involvement at lower levels, as well as, conducting workshops and the training should be based on a task analysis of all people involved with the help of training material inline with those national guidelines.

The implementation plan and scale of strategy should be prepared and experiences in demonstration areas and the model connected to experiences in demonstration areas should be fine tuned, and the accompanying budgets should include both start up and recurrent costs.

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Then the initiative should be launched with the participation of national and local authorities which would gain public and political support for the initiative, and is useful for sharing information and creating demand for community based services.

Finally, lessons learned in demonstration areas should guide the improvements in the models for a countrywide implementation. Regular evaluation and the impact on quality of care will provide the information necessary to maintain community involvement in tuberculosis.

What is the role of the World Health Organization in all of this? Well, facilitation of partner's efforts towards the partnership approach, influencing policy informed by country experience and specific recommendations, promoting partnership approach in regional meetings, national TB Managers meetings, and the international forum, capitalizing mobilization of resources, ensuring that the policies are implemented, and coordinating technical assistance with partners. Thank you. [Applause].

GIULIANO GARGIONI, M.D.: Thank you, Lana. Of course, we have time later on for questions on these presentations. We move immediately to the second presentation, which comes from a group of people that, some of whom have been directly affected by tuberculosis and who have been able to form a local NGO and are operating in Kinshasa. So, I'm calling now Maxime Lunga to

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give his presentation which will be in French and Lana will help with the translation.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: Thank you.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: Thank you organizers for this opportunity—

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: —which allows me to share the experience in [inaudible] Congo with you all.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: The presentation will be about the participation of ex-patients, ex-TB patients in the support of services and care in control of tuberculosis.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: [Inaudible] Congo is one of the high burdened countries and 20-percent of the cases in the whole country are Kinshasa.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: In 1998, an Association of Patients was born in Kinshasa with, in two health centers in Kinshasa. In 1999, this club has been formalized into Friends Club Damian and since 2001 the activities of the club have been extended to the whole city, and actually there are 30 what they call

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antennas in the city of Kinshasa, which means that they are present in 30 different health centers of Kinshasa.

And in 2005 they've been in CCM of the global front. So, they've become a member of the CCM of the global front of the country.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: It's one of the first associations represented in the CCM of the global front.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: The mission of the association is ensuring psycho-social support to the sick, as well as informing the general population of Kinshasa about tuberculosis. And the principal objective is a contribution to the reduction of the incidents of tuberculosis and the mortality related to tuberculosis in the country.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: [Inaudible] psycho-social support, their activities include IC that is health education of each new patient or [inaudible], which takes 20 minutes, house visits, encouragement of referral of suspects for a [inaudible] check-up, following up on all the folders at home. In extreme cases also providing support to patients at home with drug intake, reminding patients of the sputum check-ups whenever necessary, transport of sputa for diagnosis, and social assistance in case of stigma.

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MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: In terms of communication and social mobilization the association has regular sensitization activities in the community. Their resident conferences give talks on tuberculosis. They organize cultural days where they talk about the disease.

They are present in churches at the mass where they sensitize also the population on the disease, and every morning when there is drug intake for those qualified to come to the health center to take drugs there is a song that they are composing they sing it together with patients.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: The club is structured. It has a direction like main level sections and antennas. The selection of volunteers is a pre-established process and they are selecting volunteers among old and new patients, and responsibilities given to each new member is in the morning in the health center in the community, in the morning in the health center and in the evening in the neighborhoods which are split up according to each of the health centers.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: This is an example of how the work is organized and what you see is a catch man [misspelled?] of a health center in Kinshasa which is afterwards split in four different neighborhoods, and the volunteers that you see in the

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pictures live in these areas in order to avoid long distances. So, each of them in each of the red squares, these persons are responsible for following up patients who live in the same area.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: So, each new member of the association will be trained, supervised, and inaugurated. They have weekly meetings and they have a good cooperation with partners in Kinshasa such as Damien Foundation, which has donated t-shirts and bicycles for their work. And the success of the collaboration with the health centers will also largely depend on the motivation of the staff of the nurses at the health center because without their involvement it is not possible to have effective collaboration with the patients, because the nurse is the one who is in charge of ensuring support to the patients, as well.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: This is the change in cure rate over time from 1990 or 2000 and the patient organization has been present in these health centers since year 2000.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: This is the comparison with cure rate on the whole city on Kinshasa. The same thing in 1990 before their activities have started there has been in 65 [inaudible]. In 2005 it's over 85-percent.

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MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: Here we can see the falling rates.

Again the green bar is one of the health centers, one of the first ones where they've been present while the blue one is the whole city of Kinshasa and we can see how the trend is going down with implementation of the patient association.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: In conclusion, the participation of the tuberculosis patients in tuberculosis care has improved the case detection and the treatment results in the outcomes at the health center [inaudible] in Kinshasa, and the community participation to fight against tuberculosis improves tuberculosis care in general.

MAXIME LUNGA: [Speaking in a foreign language].

LANA VELEBIT: Thank you. [Applause].

GIULIANO GARGIONI, M.D.: Thank you so much, Maxime.

I'm now giving the floor to Mrs. Ketty Opoka whom I would also like to introduce briefly.

Mrs. Opoka is not, she is also not a healthcare worker. She used to be a teacher by profession until starting first of all to keep company and helping people affected by AIDS as a volunteer, eventually decided to give up her profession and effectively became the leader of a local NGO that over the years as you will see has been taking care of many, many people in Northern Uganda, an impressive example of how the community

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goes beyond and make a good concept of assistance to move towards the concept of holistic care. Thank you, Ketty.

KETTY OPOKA: Good morning all. I'm very happy to be here and I thank the organizers for inviting me to come and share my experience of the community involvement in care and support to HIV/AIDS patients.

An HIV/AIDS patient or a TB needs love, acceptance, and proper care so that he cannot feel alone, and that is needed by everyone. So that this person can say yes and count on something beautiful that gives meaning to his life, because no matter if they lose hope they take their sickness as a curse and when we are very close to them that is when they can die with dignity and happiness.

What is Meeting Point? It's a local NGO composed of volunteers providing support and care to people infected and affected by HIV/AIDS. It was founded in 1990 in [inaudible] Northern Uganda, and was recognized in 1994 by the government or Uganda government.

How did it begin? What is the history? In 1990 Meeting Point was founded by [inaudible], the principal of the District Farm Institute. Sick of AIDS he found a friendship in a group of friends, Italian volunteers and some African friends.

His family was the first in contact and supported by the Meeting Point. In fact the lady, the wife of Eli

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[misspelled?], the child, all were suffering from HIV/AIDS. So, the wife was the last in government hospital. She encountered some groups of friends who belonged to a Catholic movement called Christ Communion and Life. So, she went home one day very excited and she was asked by the husband what is wrong with you?

Do you take [inaudible] in your meetings? Don't you know that we are suffering, and these people will know, they will abandon [inaudible], because during those days when you have AIDS people would abandon you. They will try to run away from you even if they are close relatives, because you are AIDS is associated with immoral behaviors and secondly people did not know how one can get the infection.

So, Eli, actually the wife said today I've realized that our suffering is not for nothing. It has got a meaning. Now we know where we are coming from and where we are going. So, even if you died with AIDS or with other sickness you still go back to God, because we are from there. So, that is our Meeting Point. We start from there and we go there.

So starting from Eli, Meeting Point has always tried to give an answer to the desire of happiness. So, even if you are sick when you know where you are going you will still be happy. So, the people we met, all the sick people we met during those days they were really happy and say even sickness with its terrible things can bring happiness.

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So, that one is myself with Rosemary who refused to go home after being discharged from the hospital, because she said from home nobody would take care of her as the friends she has met. So, this photo was taken in the evening and at 7:30 in the morning she died. So, you see that even if somebody is dying they are still happy.

And we have seen so many people dying very happy. A number of people asked these friends of ours what do these people bring to you? And the only answer they could give them was, because these friends have love and care for me. There is nothing they bring like material things.

So, within the community in some areas in Kitgum District after seeing the good work done by the volunteers people in the community committed themselves to address and answer the problem of HIV/AIDS, so, it was not only depending on us.

Taking patients for treatment to the hospital, offering friendship so every patient with AIDS still has a value, dignity, needs love, care, and happiness as any other person. So, that is what was realized actually in the community and people expect to taking care of it.

So, at the beginning Meeting Point actually was the first organization in Kitgum District to provide volunteer support and care for people infected and affected by HIV/AIDS. So, the volunteers were offering their lunch, taking orphans in

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their houses because by that time there was no support from any person.

So, you have to sacrifice your lunch, you don't eat, you put that money in the pool and then you buy food and take to an HIV/AIDS patient you have encountered and the children left behind they were not taken care of, but we could take them into our houses and incorporate them in our families.

Now the aim of the organization is to accompany and value the people infected and affected by HIV/AIDS by following each patient with AIDS encountered regardless of pride or denomination to ensure that none of the friends encountered will be left alone in facing the disease and all their problems related to it, rejected by their family and society.

So, the measure of our work is leaving a friendship, a personal relationship with the HIV/AIDS patients. Help them to come up and make their own decisions, involvement of relatives, neighbors and the community to support them.

And the organizational structure, we have the foundation body with seven members, executive body with five members, and we have 14 staffs and 49 volunteers. So, these are the number of HIV/AIDS patients supported since 1990. So, you see from 1990 we, the total was 16 and then it grew up to 3,679, and you can see how the number was always increasing. So, from 1990 Meeting Point has grown not only in terms of

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number of HIV/AIDS patients, but also in the experience trying to make its presence more concrete and continuous.

So, you see the operational areas now, within Kitgum District and [inaudible] the beneficiaries. HIV/AIDS beneficiaries when you see the number from 1990 we have a total of 3,466 who are still alive. And then we have World Food Program that is giving them nutritional support. They are actually giving to 1,200. The orphans, well the children we are supporting this year was from [inaudible] to the university.

So, those are the numbers of the children we are supporting, 447, and that is the level of their education.

The donors for 2007 we have actually CRD, [inaudible] support program for all [inaudible] children that is for school fees and other needs. The World Food Program for nutrition support, CRA is for anti-viral treatment, and then we have IRCU for home based care, synthesization programs, supporting drama groups, and so on.

So, the partners within the Kitgum, we have St. Joseph Hospital, of course, we are not working alone and Kitgum government hospital has sent us in Kitgum and Parday [misspelled?], Kitgum District Director Office and Health Services. That is the DDS Office. So, all of these, we work together, because we are for that person and the health of the person.

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The activities we are doing is counseling our referral. That is where we are with the hospitals, HIV blood tests and anti-viral treatment and opportunistic infection including TB. So, patients are referred to health centers and St. Josephs Hospital in Kitgum and Meeting Point takes care of the follow up.

So, you see one of the social workers there who has gone home to visit these patients, Kitgum District TB and HIV so that is the numbers actually. You see that TB cases is increase, in 2004, 583, in 2005 614, and then in 2006, 668, so, in 2006 some of these TB patients who have counseled for HIV.

Now when you see there are only 250 we have tested and out of that 149 found HIV positive. So, TB is one of the major opportunistic infections. In 2006, 60-percent of TB patients in Kitgum District were tested HIV positive, and in 2007 from April to September 331 TB tests they did test, 170 counseled for HIV tests, 133 tested and 95 found HIV positive.

So, from April to September 2007, 71-percent of TB patients in Kitgum District were tested HIV positive. So, we also carry out home visits, when you look at that, social worker is trying to feel the temperature of this lady who is sick so that she can be referred to the hospital.

We do some home care going together with the doctors to give treatment to those who are bedridden and cannot go to the hospital now. We follow our plans on antiretroviral, provide

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treatment together with the doctors. We've also referred these clients to the religious ministers. You can see the priest giving the sacrament to that patient who is there.

And then we distribute food. You can see the clients lining up to receive sugar in the Meeting Point Compound. We also do land food distribution. That is the next, the water [inaudible] the water guard to prevent opportunistic infection like malaria, diarrhea and so on.

We also encourage these patients to do income [inaudible] activity. So does our clients who's health has improved and they are now doing what is it? It is a bakery group. So, some people come to order their bread from them in case of maybe [inaudible] and so on.

Support to the orphans, these are orphans in the secondary school where we sometimes go to visit them and talk to their teachers to find out their performances and see how we can help them improve. We have activities like synthesization programs. It can be in the community, with the patients with HIV/AIDS on how to use the water [inaudible] or give information on antiretroviral treatment, how to [Inaudible] to the treatment and so on.

So, synthesization program continues in the community. This is the group of patients with HIV/AIDS who are performing drama on the importance of antiretroviral treatment and are [inaudible] to each. Some activities we do to improve or to

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make our work go well is GEN [misspelled?] leaders meeting with local leaders, medical personal and Meeting Point counselors at community level.

We are also coordinating Connection Meetings with District Health Department partners and other stakeholders that is at the district level, and then meetings with the patients with AIDS. There is also a strong working relationship with the Clinical Offices from Kitgum Hospital has Meeting Point Clinic for opportunistic infections treatment on weekly basis. And then drugs for opportunistic infection are provided by the District Director of Health Services.

The Meeting Point Counselors go to Kitgum Government Hospital AIDS Clinic on a weekly base to counsel the patients. The District implements some activities through Meeting Point that is home based care, home visits, sexually transmitted infection synthesizatoin programs.

There is also monthly meeting on activities submitted to the DDSS office. So, events during the year which involve the patients with HIV/AIDS, we have an event during the year that is launching a book called Idin's [misspelled?] Eyes. Idin [misspelled?] is the wife of Eli you saw in the past. So, a book was written telling the whole world what happened at the very beginning.

So, that was the day. And then some events the flood that happened on the 18th, 19th of September 2007, I think you

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heard about the flood in Uganda. There was a terrible rain and so on. So our office was affected. You see how the flood is now. We had to remove all the things and leave the place, but we have started going slowly now because the water has gone.

So that is where we were transferred in a school but we are still outside. We didn't know what to do with the flood. So, in front of sickness and disasters like these money is completely powerless. So, the answer of Meeting Point to the problem of life is a companionency present within the community helping the people to face their reality in a positive way with happiness. Thank you. [Applause]

GIULIANO GARGIONI, MD: Thank you very much, Ketty and now leading to my Co-Chair [inaudible] of the next speakers.

GIULIANO GARGIONI, M.D.: [Inaudible] presentation is about the war since 1999 of [inaudible] in Peru. [Inaudible] special speaker is [inaudible] psycho-emotional support for MDR-TB management [inaudible] monetary support. The speaker is Eda Palacios. She is the coordinator of [inaudible].

EDA PALACIOS, RN: Thank you very much for the opportunity to share with you [inaudible] experience in Peru, providing socioeconomic and psycho-emotional support for MDR-TB patients.

First we will refer briefly to set model for MDR-TB curve. Then we will focus on the socio-economics of [inaudible] of the model. And then on the psycho-emotional

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support component with a special mention to the psycho-emotional support group and finally some conclusions.

Peru is [inaudible] located in South America. Its population is about 29 million, of which 44-percent are poor. Approximately 3-percent of TB cases are MDR-TB.

In 1996 Socios en Salud in cooperation with the Peruvian National ITV Program began treating our first group of MDR-TB patients with individualized treatment, setting the basis for what would be the first community based model for MDR-TB management.

It is community based because care is provided in the patient's home and the health center and together with the community.

It is [inaudible] because it addresses clinical issues, but also socio-economic and psycho-emotional problems. It is individualized, because it is targeted to each patient needs. This presentation focuses on the socio-economic and the psycho-emotional components of the model.

Socio-economic determinants for TB are well known mostly related to poverty. There is also many conflicts that they have readily been [inaudible] appropriately and certainly enough. That's [inaudible].

In Peru, medical treatment for MDR-TB is free throughout the country, but little of no socio-economic support

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is provided to patients increasing the risk of [inaudible] deepening. Socios en Salud provides this support.

Socio-economic support is targeted on the patients, but also to family contacts and the health promoter who are key for inception control and the patient recovering. Experience [inaudible] medication is necessary but not enough.

The socio-economic support needed for patient's recovery and other ends the treatment required, identifies each patient needs and providing support accordingly. Each member of the professional community based Socios en Salud team will [inaudible] in each of that recompetence of care.

However, the rules and the health promoter is specially trained in MDR-TB, our key in all three components since they are closer to the patient and the community.

Then we will conduct regular home visits to the patients who identify his or her needs, deliver care and monitor treatment and support in all three components. The social worker together with the nurse will lead on the coordination of therefore relating socio-economic support.

Socio-economic issues affecting MDR-TB patients are many and diverse and Socios en Salud addresses each of them according to each patient's needs. If overcrowding is a problem then there is high risk of transmission, it may be necessary to build an additional room in the patient's house.

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If that patient has to move to another city to receive treatment, then Socios en Solud may rent a room of which the patient in a special home where patient's coming from far away can stay for the two years of their treatment.

All MDR-TB patients in individualized treatment, as well as health promoter receive a monthly food basket. Socio-economic support is required also for aspect of medical treatment, not recovery by the [inaudible] of health such as auxiliary diagnostic tests and consultation and drugs necessary to combat side effects.

Patients receive medication in the morning in the health center and in the evening in their home, whether they are administered by a health promoter sometimes transportation will need to be covered for the patient and or the promoter.

We also provide support for income generation initiative and resumption into the workforce. Now the Director will refer to the psycho-emotional support component of the model. [Applause]

JULIO ACHA: Whatever Eda wrote in the health team is we should always remember that we work with people not with illness or microbe.

Each individual has a [inaudible] which influence how he or she will react to diagnosis and face the disease. Once diagnosis the person will need to learn to accept the disease

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and the treatment, side effects, and limitations, but we also have to fight against social system.

Socios en Salud nurses have identified several situations faced by MDR-TB patients for which emotional support is necessary and which you can see listed here. I would like to emphasize guilt, stigma, affluence, side effects, and socio-economic difficulties such as losing their job, failure to current or previous treatment, and [inaudible].

When you indentify needs and targeting support, we not only look at the psycho-emotional and psychiatry problems of the MDR patient but we also consider and provide support to [inaudible] team. They all mentor health and ability to provide psycho-emotional support to the patient may be affected by possible situations relating to the disease treatment and the care they provide.

During the illness patients will go through each step of grief, denial, feeling of guilt, anger, depression, acceptance of the disease. The most important step is guilt. Relationship with family and friends and others, as well as, most aspects of the person's life will be affected somehow by the disease and its treatment. The person will need support o handle these changes appropriately so that they don't negatively affect their recovery and positive attitude.

It will be necessary also to evaluate and manage personality disorder or mental disorder, which may be present

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prior to MDR-TB treatment. The [inaudible] Clinic for psychiatry disorder we found during the treatment our psychotic disorder and depressive disorder. We will also need to manage psychiatry disorder side effects using a typical anti-psychotic, anti-depressive such as SSRI's.

In our first 75 patients we observed that 52-percent had depressive symptoms when they start the treatment, while only 20-percent had the depressive symptoms during treatment. These patients received psycho-emotional and socio-economic support.

Although none had psychotic symptoms at the beginning, 10-percent did have them during treatment probably due to psychosery [misspelled?]. These patients received a typical anti-psychotic and continued their MDR-TB treatment. Only 1-percent of the patients with psychotic symptoms require treatment in a psychiatric hospital, however, they only require a short stay.

In order to timely and manage psycho-emotional problems we work closely with the patient's family and [inaudible] team, especially with the mental health team, health promoter and also psychiatrists, psychologists and social workers. Also in the rest of the components of the community based model, the nurse and the key health promoter play a key role.

The healthcare personnel responsible for delivering treatment and the promoters who visit the patients daily are

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prepared to identify [inaudible] symptoms quickly, suggest emotional or psychiatric disorder and to seek help accordingly.

There are several ways in which Socios en Solud provides emotional support to MDR-TB patients. Some are informal like the daily visit, a companion to patients, and some others are more formal, psycho-emotional support roots being the most important.

These groups are conformed by 15 to 20 patients who meet every two weeks with a therapist and co-therapist during two hour sessions to share and discuss their worries and problems and support each other. Patients have to be tutored and they have to participate in this group. Psychotic patients are temporarily screened.

During these group sessions the therapist and co-therapist will help eliminate guilt, stop looking for the contact, accept the disease, its temporary limitation and side effects, add that to specific situations MDR-TB treatment side effects, family problems. Don't forget help them to eliminate the guilt. The guilt is the tuberculosis of the soul.

In our experience, psycho-emotional groups played an important role in helping patients accept and overcome their long and difficult treatment and [inaudible]. They also allow interventions in case of suicide risk.

But the advantage of patients sharing their testimony and giving support to patients has proved very effective. All

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of the tapes on how to prepare and conduct these core groups can be found in Socios en Solud manual [inaudible].

In this chart the blue line represents our inundate rates in the MDR-TB patient receiving [inaudible] treatment in Peru. The red line shows our indundant [misspelled?] rates for individual [inaudible]. We can see our inundate [misspelled?] rates are higher in [inaudible] treatment, although both treatments are ambulatory [inaudible] lacks the socio-economics and psycho-emotional support component of [inaudible].

We suggest that this supports to patients [inaudible]. Finally MDR-TB requires a long and difficult treatment. We must grant that patient will receive the pharmacological, economic and psychological means they need to combat the disease. This is especially important in resource limit setting, community based conferencing [inaudible], care and [inaudible]. Thank you. Muchos gracias. [Applause]

GIULIANO GARGIONI, M.D.: Thank you, Julio. The next speaker is Linking and the MDR-TB and HIV Prevention Management Through the Community Health Worker. Maribel Munoz, she is the coordinator of [inaudible].

MARIBEL MUNOZ, RN: Thank you very much for the opportunity of sharing with the experience of Socios en Solud [inaudible] together with [inaudible] model for MDR-TB and HIV/AIDS management in Peru.

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I will refer to how we have started our community based model in [inaudible] model. Then I will review the characteristics and roles of [inaudible] for model.

Looking to the [inaudible] MDR-TB and HIV/AIDS management and finally share with you some of our challenges.

In 1996, Socios en Solud [inaudible] Lima. At that time [inaudible] TB was not considered [inaudible], because treatment was long, complicated, and very expensive. However, Socios en Solud managed to [inaudible] treatment for a first group of [inaudible] patients.

Little was known about [inaudible] TB and we often fall in the [inaudible] regiment. [Inaudible] patient has to implement [inaudible] treatment the possible side effects, to guarantee the patient would take their medication, to provide emotional and socio-economic support to [inaudible].

At that time, Socios en Solud [inaudible] within the community together with promoters of community agendas, so, [inaudible] on the long treatment.

Additionally [inaudible] combination in the management of TB, but there was no similar experience with MDR-TB. Peru has [inaudible] country in Latin America has a long tradition of community organization in pursuit of [inaudible] for every kind of problems arising from poverty.

This ability of community or organize, [Inaudible], to identify their leaders and [inaudible] for common objectives.

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[Inaudible] model in prevention in the promotion of
[inaudible].

In Socios en Solud it's more [inaudible] promoters are involving also in MDR-TB treatment delivery and supervision. [Inaudible] traditional role [inaudible] recovery and this is with characteristic [inaudible]. [Inaudible] to the [inaudible] but becomes a member of the team but without losing his or her [inaudible] to that community.

Since this [inaudible] supported the [inaudible] MDR-TB patients [inaudible] Lima. At one time there were up to 700 promoters delivering individualized treatment and which is approximately 2,500 patients. [Inaudible] MDR-TB treatment is provided to help certain regions in Peru.

Since year 2003 only a few cases of MDR-TB and HIV co-infection were detected [inaudible] MDR-TB, promoters were training also [inaudible] and the retrovirals [inaudible] and side effects. The [inaudible] his or her community work [inaudible] constantly seeking a [inaudible] for his or her community. This means the patient may or may not [inaudible] relating issue by receiving training on TB, MDR-TB, and HIV/AIDS to accompany the patient during the treatment process. [Inaudible] relationship with the promoter and the patient.

Usually the MDR-TB promoter is chosen by the health professional from the health center where the patient is to be treated. In our space experience promoters shall not be family

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or a relative of the patient. Each promoter should be responsible for not more than three patients.

Promoters accompany the patient through HUB [misspelled?], their 18 to 24 months of MDR-TB treatment. During this time and because HIV treatment is life threatening, they will prepare the patient for self administering of antiretrovirals and for treatments [inaudible].

Identify and preparing a person from the family or someone chosen by the patient to help her overcome the difficult moments of HIV/AIDS treatment and MDR-TB treatments [inaudible] and the promoter is no longer too.

[Inaudible] main role. Promoters and promoters [inaudible] within the family, [inaudible], and the community.

[Inaudible] translation, the language and they're all colleagues. [Inaudible]. During the daily visits to the patient's home and in coordination with the health center, the promoter [Inaudible] and supervise treatment, but if the opportunity [inaudible] emotional changes in the patient.

Reporting [inaudible], because promoters are closer to a patient they are in a [inaudible] position to look into other issues [inaudible], especially socio-economic and psycho-emotional.

They participate in training and participate in workshops, director, the promoters and also health

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professionals such as nurse. [Inaudible]. They conduct [inaudible] and identify research problems and [inaudible].

But if our [inaudible] monetary and supervision by the field supervisor, usually no technician [inaudible] responsible MDR-TB management is [inaudible]. It is also necessarily important [inaudible] between the promoter and the patient is going.

[Inaudible] and working with health promoters in MDR-TB and HIV/AIDS, management may [inaudible] and during the time of initial crisis of project implementation that's got many advantages. [Inaudible], patients [inaudible] treatment is optimized. [inaudible] TB or HIV.

This chart shows a [inaudible] treatment in patient receiving [inaudible] treatment [inaudible] in Peru.

[Inaudible] treatment is one of the main difference between the treatment [inaudible], that the promoter may play a positive role in [inaudible].

In 2005 the Peruvian National HIV Program with the help of Socios en Salud [inaudible] of enrollment of HIV payments into antiretroviral treatment. That blue line shows the enrollment [inaudible] of health promoter while the red line shows enrollment with involvement of [inaudible]. In the ninth month of the program 124 patients per month were enrolling, while in the last seven months 226 patients per month were enrolling [inaudible] person.

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Some of our current challenges are to continue [inaudible] basic model with hyper-model in Peru and other places. [Inaudible] of the model involved. [Inaudible] from the promoter to HIV patients. [Inaudible].

Finally I would like to end this presentation with the words of Carlos. From all the many MDR-TB patients that have [inaudible]. Mucho gracias. [Applause]

GIULIANO GARGIONI, M.D.: Thank you Maribel, any questions for the panelists? We still have one more presentation and then we'll have about half an hour for questions or perhaps your contributions.

LASNA GOGUADZE: Good morning, many thanks for the opportunity of being with you and to share with you one more, in our view, good experience addressing TB and HIV at the community level. And I see that if we bring together all of our sense just what was presented during this morning so I think it's enormous forces to find.

First let me introduce myself. My name is Lasna Gogvadze. I represent the International Federation of Red Cross and Red Crescent Society's. They bring together 185 national Red Cross and Red Crescent Society's worldwide. This is the biggest humanitarian organization.

In our momentum, we have international community of the Red Cross; International Federation of the Red Cross, Headquarters based in Geneva and [inaudible] National Red Cross

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and Red Crescent Society's worldwide through their countrywide networks and tens of millions of volunteers.

This triangle shows what is our approach generally in our programs. We address prevention. I mean we have the stigma and discrimination attached in both situations. And we are involved in care and support of people affected with HIV and TB.

To give you some idea of where we are in what we really focus, I would like to present these tapes [inaudible] that shows our role as identified by the Red Cross, Red Crescent Society's and TB control.

So, we are community based organizations. We are not medical organizations. We don't take responsibility of technical part of TB control in this case. So, of course, this responsibility stays with the health authorities and with other technical partners. We see our role in the first and the third links in prevention, in health education, in case finding, and of course, in social care, psychological support and [inaudible] support.

Currently we have tuberculosis activities in the countries that are listed there, and I hope that in those countries that you present [inaudible], in Uganda, in Congo, I hope that they soon our Red Cross Societies will join you in your good work.

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I would like to share with [inaudible] specific experience that's coming from Santa Alaysia [misspelled?] and [inaudible] so where we implement tuberculosis and HIV/AIDS programs and there is no secret that in many cases these programs nationally also go parallel.

And of course we have so many STD programs, HIV programs. For the last two years we've tried to bring these activities together. Programs are supported by British Red Cross and AstraZeneca, and since 2004, we tried to integrate TB and HIV activities.

So, I would like to share with you through whom we are implementing these programs. These are Red Cross and Red Crescent family nurses, volunteer psychologists that provide the [inaudible] or director of the organization combined with the social support. They do case finding.

Again as mentioned before, they do case reporting. We try to organize the support groups. We do care education. Also just to give some ideas about other activities that link to HIV prevention and because you know that in Santa Alaysia [misspelled?] HIV/AIDS is very much linked to the intravenous drug use. So, to address the HIV problem, it is impossible not to get involved in the problems related to the drug use and particularly the intravenous drug use.

So, we have syringe exchange offices, condom distribution, promotion [inaudible] and testing. Society is

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involved in the legal support wherever is needed and possible and also education and awareness.

Our targets in TB programs [inaudible] are tuberculosis patients in post hospital phase. [Inaudible] drug resistant TB patients, their family members, and entire communities.

Here I listed, I wanted to share some achievements and currently they are involved in seven sites over a 1,000 beneficiaries targeted, so, 67\$ in the projects sites. It is not nationwide statistics.

And in our sites where the Red Crescent is involved over 80-percent success rates are reported. And it will take in the sites where the Red Crescent is involved is about 1.5, so, meaning if we take 100 most vulnerable patients or clients in our activities or we try to follow them regularly on a daily basis until they finish the treatment.

Of course we can't take responsibility to cover all needs. Therefore, every society depending on the country specificities have their criteria on so who is included in our programs. These are basically the most vulnerable among the vulnerable.

So, these are target groups in our HIV programs, youth, drug users, sex workers, military, long distance drivers, labor immigrants. So, those who are at most risk of risk for HIV transmission.

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So, I mentioned that societies focus is the peer education and we do that to our peer educators and so here Society wants to share with you some achievements that they managed.

So, they managed to have hundreds of peer educators from the different target groups, from sex workers, from intravenous drug users, of course, from the people with HIV and AIDS. So without them it would be impossible to have any success in the activities.

We try now to bring all those for years parallel going activities together somehow, and, of course, due to the conditions that are presented there. In the country TB rate was going up. TB drug resistant, the number of TB drug resistant cases was going up. HIV cases was increasing, 77-percent of the HIV cases or main mode of transmission is intravenous drug use.

TB is diagnosed in over 45-percent of HIV cases and 60-percent of death among HIV affected is associated with TB. So, I mean, of course, it's more than enough reasons just to put those efforts together to address TB and HIV in an integrated way.

And the focus of the program was, of course, on the psychological assistance and prevention of tuberculosis among risk groups for HIV and among people living with HIV. That's our target groups of the project.

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Of course, certain needs assessment was done and, of course, it included medical aspects that are listed there. So, available services at the site level of different medical services. I mean access to antiretroviral, different diagnostic services related to HIV or in general of some preventive check up.

Needs assessment included, of course, social aspects, meaning the availability of care and support services in the project sites. What is this? I'm sorry. Yes, [laughter], anyway and, of course, the legal basis in our project sites.

Confidentiality and anonymity was kept there. So what was the discrimination level of people affected with HIV, and, of course, whether it included access to the medical services and different [inaudible]? That information was absolutely necessary to design the activities of the program.

Society developed this [inaudible] team. I mean social worker so caregivers, psychologists, and the legal advisor, of course, the client was in this center.

So, our main achievements again the project sites, the biggest achievement is that without those 28 social workers from the group of affected with HIV so we would not manage to do anything. So, we somehow managed to [inaudible] to increase the treatment completion rate and the success rate. Completion rate went down. I mean default rate went down from 66-percent to 13-percent and success rate up 66-percent.

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Of course, we are talking here about the small model in the country and, of course, one of the main objectives in the nearest future is just to expand [inaudible]. So, the staff and volunteers of the Red Cross Red Crescent regularly receive training and we would like to see them tomorrow as critical partners to the inside of the system of the human resources of the Health Ministry.

And to our activities we would like to advocate for the stronger voice of the community [inaudible] societies. So, again I would like that in the future we work in more and more countries together. And please when you go back please contact your National Red Cross or Red Crescent Society because they can give you a huge help. Thank you. [Applause]

GIULIANO GARGIONI, M.D.: Thank you very much. Thank you all the speakers actually for sticking to the time assigned. And we have now about half an hour, which we will be very pleased to have questions from you but also contributions from people who have been involved in the community initiatives.

I would like to ask all of those who wish to intervene to go to the microphone at the back of the room and please identify yourself and the country you are from and tell us please also to which presenter you are directing your question.

ANTHONY: Good morning, I'm Anthony. I'm from [inaudible] in South Africa. I have a general question to all

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of the speakers. You were talking about volunteers. I would like to know what is the definition of a volunteer. Is it a person that is getting paid for what he is doing, or is it a person that is doing things free of charge? I think that is quite important for me, because here in this country where I am we have a new concept of volunteers where we pay people stipends and then still call them a volunteer. So, I just want to know that is the concept throughout all of the world.

Thanks.

GIULIANO GARGIONI, M.D.: Thank you for your question. I think I would like to answer this question because this has been specifically one of the objectives of the [inaudible] guidelines for community involvement that is now being finalized. We have to consider to answer your question the reality of community participation after a matter I think.

A matter proposed [inaudible] like a community health workers and traditional work attendants that are trained by health professionals but are not health professionals. These are people who have been also called volunteers but these are people who devote a significant part of their time and sometimes their working time to serve their communities. It is, therefore, right to and obvious that these people receive some compensation, perhaps not monetary compensation but some compensation from their own community.

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But at the same time we have seen today examples of personal support within the family, within the neighborhood, from friends, personal support that perhaps may be limited to five or 10 minutes a day but which is very, very essential. So, we don't think that people that provide 10 minutes of their time are less important, on the contrary, than people that do it as a more like a commitment or a profession.

Therefore, I think your question sheds some light on the fact that we should distinguish from volunteerism doing things out of our own generosity and voluntary work, which is a very important positive decision and acceptance responsibility by community members. Then this voluntary work may take a short time, and obviously may not be enumerated, because people will do that happy to serve themselves, their families, and their community, or it may take a significant amount of their time and then it is absolutely right that as a part of the design of the community intervention the community thinks about compensation for these people.

FEMALE SPEAKER 1: Hello, I am from [inaudible]. I would like to know how are we going to help the situation in the [inaudible] whereby is the health workers seems not to, how they look that their promoters are a threat to them. Is there any plan made that can integrate the two so that they can be on the same boat?

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GIULIANO GARGIONI, M.D.: Thank you for your question. The question is about [inaudible] health workers being motivated in involving communities and not perceiving the participation of the community almost as a threat to their profession. So, I think given that today's presentations were most about practical experiences I think some of you may have significant things to report.

FEMALE SPEAKER 2: [Inaudible].

GIULIANO GARGIONI, M.D.: Use the mic, please.

FEMALE SPEAKER 2: Okay, [speaking in a foreign language].

FEMALE SPEAKER 3: So, the community health workers or the health promoters are part of the community in which they are working. So, they're not just working with tuberculosis. They're also working with all of the other social and health conditions within their community. So, because they're a part of those communities they're very involved in all aspects of the work there. Does that answer your question? Do you want to know how they motivate them to be-? [Inaudible]

FEMALE SPEAKER 1: [Inaudible].

FEMALE SPEAKER 3: How they get the community to work with them?

FEMALE SPEAKER 1: No.

FEMALE SPEAKER 3: I'm sorry.

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FEMALE SPEAKER 1: What they have to work on? I think [inaudible]. What is the [inaudible].

GIULIANO GARGIONI, M.D.: I think now the question is [inaudible]. I think one of the major points about community involvement is precisely the fact of improving access. So, the reality today is that it's not that we have too many health workers and too many promoters and too any community health workers.

It's the opposite, so, I think the way forward is for people to recognize their own [inaudible]. Health professionals right now are seriously over burdened within health facilities, and it is good for them to concentrate on that work. We should not force them, we should not pretend that on the top of all that they have to do they all should move to the community.

Now there are people who are from the community who belong to the [inaudible] of the community know better everybody within the community, these are people with whom we need to establish a partnership. It's not a matter of jealousy here because each one can contribute a different richness to the achievement of the common good I mentioned at the beginning of this morning is [inaudible] for everybody.

So, it's very important to recognize that different people can play different roles and different people can have

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different kind of proximity and service [inaudible] to the people who are suffering.

MALE SPEAKER 2: I would not be very modest to say that even if that's very effective and very cost effective and most efficient way to own the ground work is not, it cannot be effectively performed for free. It needs investment and it needs constant capacity building. And in my view it should be one of the major parts also financially in the national tuberculosis programs.

They have to be really acknowledged and it has to be a part of it. If it is part of the 26 [inaudible] strategy it should be well reflected in the national program so it needs a regular development and the investment. It can't be free.
[Applause]

GIULIANO GARGIONI, M.D.: Thank you. This is precisely why the point is being included in the strategy with the hope of influencing governments in the new policy. We have another question.

MALE SPEAKER 3: My name is [inaudible] from Kenya. I am the original coordinator for TB. I actually have two questions. One is just a follow up on the work we've been talking about with [inaudible], something to motivate the supporters or promoters in the community health care workers.

So I just wondered if maybe the previous presenters could tell us what motivations do they have for the healthcare

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promoters and supporters to keep them on the job, with four months following up one or two patients is not a small job so I wanted to do you have an idea of what stipend they offer.

The second question is that we all think that as family members or friends we have the interest of our friends at heart. So, I was a little taken aback by the characteristics you offered for health care worker, community health care worker or promoter when they excluded family and friends I have read about these studies and I am interested in the [inaudible] have done research myself. I have a different theory myself. So, I wanted to see why are they excluding the family members and friends?

GIULIANO GARGIONI, M.D.: Okay, this question I think goes to [inaudible] and then also Maxime would like to answer that. Let's start first from the experience of the health workers. [Inaudible]

FEMALE SPEAKER 4: [Speaking in foreign language].

FEMALE SPEAKER: So, the first part of the question about motivating the community health worker to stay in the program is really because they're part of the community. And the smile of a child is a lot of what motivates the health worker there.

FEMALE SPEAKER 4: [Speaking in foreign language]

FEMALE SPEAKER: Often in terms of compensation the health workers do receive food baskets, monthly food baskets.

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And they receive compensation for transport for visiting the patients.

In terms of the question about why we don't use family members for DOT is because since 1996 we've had the experience that with our patients the adverse effects of the medication actually sometimes prevent family members from administering the medication. They see their family member suffering so much from these adverse effects that they stop administering the medication, and it's really for the patients' benefit that we ask that it not be a family member. It's to protect both the family member and the patient from being in a really terrible situation.

FEMALE SPEAKER 4: [Speaking in foreign language]

FEMALE SPEAKER: In terms of our HIV work because of lifelong treatment we actually are helping to train the patients themselves to do self-administration of the ARV's and in that situation we do have a family member help be a support system for them in terms of reaching self-administration, achieving self-administration. So, it's a little bit different in the HIV program and that support system kicks in around eighteen to 24 months.

FEMALE SPEAKER 4: [Speaking in foreign language].

FEMALE SPEAKER: And again in the situation of HIV the original health promoter does continue with follow up if the

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patient. It's just not as direct a way and as continuously but they do continue follow up every couple of months.

FEMALE SPEAKER: Another contributor Maxime Lunga from the Patient Association in Kinshasa.

MAXIME LUNGA: [Speaking in foreign language].

FEMALE SPEAKER: We are about the motivation of ex-patients involving TB control.

MAXIME LUNGA: [Speaking in foreign language].

FEMALE SPEAKER: The personal motivation is the personal interest in stopping the transmission of the tuberculosis because these are the persons who have the experience already of the disease.

MAXIME LUNGA: [Speaking in foreign language]

FEMALE SPEAKER: The motivation is the results that are being achieved with the involvement of the ex-patients because the ex-patients who help the new patients they see them get better and this is very rewarding.

MAXIME LUNGA: [Speaking in foreign language]

FEMALE SPEAKER: And finally lots of patients as they get better and they get cured they thank the health worker for helping them take their drugs but they also thank the patient association which is much more worth to them than the money that they could receive for their work.

MAXIME LUNGA: [Speaking in foreign language]

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FEMALE SPEAKER: Tuberculosis is very stigmatized in DRC [misspelled?] and the fact that the old patients are getting recognition, first as human beings through their work and they have a good relationship with the health staff is very empowering for them.

MAXIME LUNGA: [Speaking in foreign language]

FEMALE SPEAKER: Of course none of this would be possible without the financial support of our partner agencies operating on the ground in Kinshasa which are not financial incentives to individual volunteers but are more things like bicycles, t-shirts, training, pen and paper to record their activities and so on.

MALE SPEAKER: Please, we have time for one or two more questions.

MALE SPEAKER 2: I would like to express my concern about involving HIV positive patients in TB care. And asking for some of experience regarding it as we know it's probably a very dangerous activity [inaudible] HIV positive to care for TB patients that particularly is [inaudible]. So, do you think or [inaudible] we should recommend that they are excluded from this activity and what about providing a specific package for those volunteers like doing [inaudible] even though it may not exist at a wide scale in their country.

The other point is I am really concerned by the fact that there are a lot of finding and activity going specifically

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for one community based organization which is very good and very important and can complete the public health services activities. But I think we should really look carefully at what's going on in these public health services, because it may be a very good reason for them not to question themselves, not to hassle with their primary missions. It's good that they're often over burdened.

But sometimes they just don't care, and if as has been said for Kinshasa it is the public, the volunteers who are teaching the nurse to do his job. That's a very positive thing but it's a bad time for the health services. So, I would like and I mean I wonder why in [inaudible] we see that when there [inaudible] are increasingly having a high defaulting rate. You can have people not following their treatment because they know that they don't benefit from that support and basket of food. And then we just create discrepancies and some kind of more problems for the public services.

GIULIANO GARGIONI, M.D.: Question in several parts so first the reply from DRH.

FEMALE SPEAKER: I think it's best if we reply to the part about failure. We don't have HIV patients treating as health promoters for our TB patients so that's not something that we can necessarily answer. Perhaps one of our other colleagues can but I will ask about our failure rates, as well.

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GIULIANO GARGIONI, M.D.: I will take the time to reply to the question [inaudible]. Well obviously we don't have any recommendation about specific involvement of TB people affected by HIV infection to volunteer work with the TB patients.

It may happen, but obviously in the context of our TB/HIV collaborative activities we recommend a very good screening for any symptomatic HIV positive person.

[Inaudible]. So, this should be done even before the person becomes involved in any voluntary work, very good element in my view. The second part of your question in which you ask, well are we not involving the community because the health services are not committed in a way?

And my answer through many years of experience and also through the working [inaudible] is that we should realize that community initiatives do not work if the health system is not functioning well. They simply do not work. Delegating to the community what the health system doesn't want or cannot do is not a solution. The involvement of community requires a more mature health system not a less committed health system.

[Applause]

FEMALE SPEAKER: So, in order to save a little bit of time I'm just going to say this in English. So, in terms of the NGO's, is this on?

MALE SPEAKER: Yes.

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FEMALE SPEAKER: Okay, in terms of the concern about NGO's either replacing or superseding the public health sector that's exactly the opposite of what Socios en Salud does and has been doing for the last ten years. We've been collaborating with the Ministry of Health.

We have been increasing capacity at the Ministry of Health and we really have been integrating the services that we're promoting with the Ministry of Health services. We are completely integrated with them and-

MALE SPEAKER: My question is don't you think that it may create some discrepancies that some people will say, oh these people they are supportive. I am not attacking you. We are not in the U.S. [laughter]. Relax.

FEMALE SPEAKER: Or in Iraq for that matter.

MALE SPEAKER: But no it can happen. It happens. When people say, oh I don't have that disease, or I am not supported by this program. So, I'm going to drop my treatments. That's my question, what do you think about that possibility.

FEMALE SPEAKER: You know what? I don't, from our perspective people don't fail treatment because they're not receiving the extra support of the NGO. We would love to give extra support to the entire population and it's simply that we can't.

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And the Ministry of Health would love to, as well. But they're not able to, financially they're not able to. In terms of human resources they're not able to logistically.

So, [laughter] this is [inaudible]. He is our Director of Socios en Solud, and has been working on this for the last fifteen years approximately, more than ten years. So the standardized regimen from the Ministry of Health wasn't working. So and that is why Socios en Solud stepped in and started doing the individualized regimen with the social and economic support.

MALE SPEAKER: [Inaudible] that is the question.

MALE SPEAKER: I think that is a very valid comment and very valid situation, especially in my country where first we were facing a very difficult public health threat which was MDR-TB. At first we were offered to receive the standardized treatment and that's it just medicine and no more.

And we were told that if you don't receive this is going to be your last chance to receive treatment and there is nothing more beyond that. So, if you fail this treatment that's it. So, the patients that were receiving that treatment were not doing well and there were no financial aid coming from the government or from international agencies to do more. It's not that money was not available.

It's that the patient were not receiving the financial support that they needed at the time. On the graph what is

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showing data that happened around 2004, right now we are talking to a situation with the government moves the budget from \$3 million to \$10 million.

So, that means commitment from the government and right now you have not just [inaudible]. You have a food basket, you have covering lab tests for the patient, you are covering all of their activities and some of them are coming from the government. Others are coming from the international agencies. So, what we actually were doing is that here there is a gap what can we do to close that gap?

So, we were [inaudible] that at some point of the history where we have two different treatments one that didn't go well and the other one that was going well. The difference couldn't be just the treatment, one wrong treatment and the other a good treatment.

It must be something else. So, there is no magic bullet on the medicine. There must be something else, human factors helping the patient to cope with the treatment, eighteen month treatment, 24 month treatment. There must be something else.

So, food basket, [inaudible] transport, no fees for lab tests, etcetera, et cetera, and the government knowing that it was working well so they started taking responsibility in covering the budget. So that is what's going on and the

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budgets coming from international agencies are less and the budget coming from the government right now is more.

So, this is still a process going on. I hope that that helps to clarify your question.

GIULIANO GARGIONI, M.D.: Thank you for your reply. I am sorry because the debate is becoming interesting but unfortunately we have to leave, so impossible to summarize the number of important points and suggestions and [inaudible] and challenges that have emerged. But at least we should take home one message. There is much more out there than we do imagine as workers, as health professionals. There is much more in terms of ideas, initiatives, resources, commitment out there than we do imagine.

So, let today's meeting and thank you for coming to an early morning session. Let today's meeting be an encouragement to go beyond, to go forward whatever are our goals, community members, health professionals, and so on we can promote a dialogue with each other and we can promote the involvement of people for the better empowerment for their health.

Thank you very much and have a good day. [Applause]

[END RECORDING]

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