



## Ivermectin Use in Kisoro in Dispute – A Researched Rejoinder with Focus on Women

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### Abstract

*Sparked off originally by the Sudanese academic Homeida, in a short account implying that a majority of women in Kisoro were nonusers of ivermectin, the current study is out to see if that position is viable enough to withstand careful research of the matter. Fieldwork, which helps us to show what can be and is known of Kisoro inhabitants, both in the past and in concurrent times, in terms of disease treatment and control, occupies center-stage. Choice village societies, believed to be havens of elements supposed to be against treatment by conventional medicine, ivermectin included, were the main hunting ground. The conclusion from the findings, at the end of the day, is the opposite of the view touted by Homeida.*

Ultimately, this study springs from comments by the Sudanese scholar Mamoun Homeida.<sup>1</sup> He made them during the March 2004 Annual Program Review of The Carter Center Global 2000 in Atlanta, Georgia, USA. Homeida observed that some of the statements and figures by Habomugisha (2004) seemed to argue that onchocerciasis sufferers and the disease’s potential victims, in Kisoro District, Uganda, be they male or female, were almost equally favorably disposed to the use of ivermectin.

With reference to a past report by APOC’s Technical Consultative Committee (TCC), Homeida said that, there, women, who were eligible for the drug, were not taking it in big numbers unlike their male counterparts. “The project provides reasons for high refusal rate among women in Kisoro,” reads one recommendation by the APOC-TCC (2003) – among other comments on a 5<sup>th</sup> year technical re-

port about the “phase 1 CDTI project” in Uganda.

Authors of the (technical) report, which, it is noted, was “well written”, are not named in the APOC-TCC document, nevertheless. A search by this writer did show, though, that it was produced by NOTF-Uganda, although efforts to locate this document were fruitless.

The cited recommendation, undoubtedly, appears to be saying that men, who take ivermectin in the district, far outnumber the women users of the remedy. This is in dispute with my older knowledge of CDTI in Kisoro District. It was in reply to that contradiction that I took it upon myself to research community attitudes towards treatment with ivermectin and other modern medicine, in that district, with special regard to women in some of the region’s “religious cults”. New research, such as I attempt down, is clearly our main hope for a credible answer to the two apparently opposite stands. My

probe, hopefully, will sharpen and extend our knowledge of onchocerciasis programs in the area – not least their popularity or lack of it, their benefits and their other obstacles apart from unpopularity.

The study proper starts with some geographical, socio-political, demographic and religious information, after which we have a review of the district’s contemporary health order, a survey of the strategy of community-directed intervention (CDI), reasons and explanations given to justify why I found it sensible and important to take up this research, study’s aims, matters of research methodology, results of the investigation, discussion of field notes, and a short conclusion that completes our journey into the issue under scrutiny. All of these items are dealt with one after the other, beginning with the first

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<sup>1</sup> Currently based in Khartoum, Sudan, Dr. Homeida chairs the Academy of Medical Sciences and Technology there.

and closing with the last. Sections up to the methodology part inclusive are background material to the matter at issue. Everything else, thereafter, is, openly as well as indirectly, a head on effort to resolve the question up for discussion.

### **Facts of Geography, Demarcations, Demography and Religion**

Kisoro District is located in a remote mountainous area in the southwestern part of Uganda. It borders the Democratic Republic of Congo in the West, Rwanda on the South, Kabale and Ntungamo districts to the East and Kanungu District at its northern flank. The district is divided into 14 sub-counties and 386 local council communities (LC1s) out of which 32 are onchocerciasis endemic. Kisoro has a population of 221,427 (according to 2002 Uganda national census provisional results) of which over 90% are peasants.

Home to many religious traditions, which include, but are not limited to, Islam and Christianity, the land is prone to the appearance of “cults”. With what are usually deemed fanatical and/or dangerous lifestyles (teachings, expectations, rites and other activities), these groups are particularly found among Christians in the district. Cult, such as in “religious cults”, in this work, consequently has the narrow sense of a referent to mainly Christian sects, such as the Barokore (“the saved ones” or “the born-again”) about whom we are yet to hear more.

### **Existing Health Care Delivery Systems**

Kisoro, like any other district in Uganda, has a health department under the District Director of Health Services, who is deputized by 3 medical officers at the constituency level.<sup>2</sup> The department is mandated to implement the National Minimum Health Care package among the people through already established Primary Health Care (PHC) systems. Below the constituency level, the delivery and manage-

ment of health care service are decentralized to the 14 sub-counties of the district. At the sub-county level there is a health team composed of clinical officers, nurses, nursing assistants and health extension workers. Health workers, at this stage, are supposed to offer to people such health promotion services as curative and preventive medication down as far as the household unit. But this has not been the case. These health workers are overloaded with daily clinical activities, and hardly get time to visit the communities. Even if they had the time, the distance from the health centers to most communities is too long with no means of fast modern transport. Due to these constraints, it has been rather hard for the people at the community level to receive services from health workers.

However, community-directed intervention (CDI) offers a rare escape from the dilemma. Experience, from community-directed treatment with ivermectin (CDTI), shows that people can productively be involved in disease prevention and control within their communities.

### **Community-Directed Intervention (CDI)**

A community-directed intervention is a health strategy that is undertaken at the community level under the direction of the community itself. Health services and their partners, in a participatory manner and with the ideal of ownership by the community as their focus from the onset, introduce possible intervention(s) and the concept of community-direction. From then on, the community takes charge of the process, usually through a series of community meetings combined with implementation by selected community members. The particular community, health services and other partners all have roles in community-directed interventions.

Community-directed intervention was in 1997 launched in Uganda. Ever since it has been used successfully by the river blindness program. Later, in 2001, this strategy was recommended by the government of Uganda as a policy to be fol-

lowed countrywide by communities in health and developmental issues. Uganda’s Ministry of Health (MOH), to mention a connected detail, has also recommended that the CDI approach be used in all community disease control programs, including malaria, tuberculosis, diarrhea and others. The same ministry also has advised that community-directed health workers (CDHWs) be trained to take up other supplementary health services to enhance integration of CDTI into PHC activities. It has, as well, recommended that the MOH and local governments implement the formation of village health teams (VHTs) and ensure that they function to deliver village health services.

Kisoro District, with the support of APOC, implemented CDTI, with remarkable success, from 1998 to 2003. One external evaluation report described Kisoro’s CDTI program, during the year 2002, as making satisfactory progress towards sustainability. Weighty independent recommendations, from that year and in the same report, reveal that APOC was poised to consider supporting capacity building, leadership development and data management in districts, such as Kisoro, that had made sufficient headway towards maintenance of CDTI. The district was apparently also cited as distinguished for improved linkages between local councils, sub-county health staff and communities – links that did enhance CDTI and other PHC activities at community level. In May 2003, Kisoro District, during a workshop on sustainability of community-directed interventions for multi-disease control in the health sector, decided that CDI be adopted everywhere within its boundaries. The workshop further recommended that the district submit a proposal to Global 2000 for support and funding of its resolve to implement CDI.

### **Rationale**

Community-directed treatment with ivermectin, against onchocerciasis in the GRBP districts in Uganda, has

<sup>2</sup> Known also as “health sub-district level”. On “constituency”, we may observe that individual districts in Uganda consist of several political units, each of which is identified by that descriptor. Each one is coterminous with a county.

proved to be effective. Also it has demonstrated its ability to sustain the desired coverage of ivermectin distribution since it was introduced. Our authority, on both counts, is the general field experience of the different parties with a stake in the venture. The major aspect in this strategy has been community involvement, which emphasizes community ownership of the program, and, down the road, maintenance of the undertaking.

Local government's decentralized system, from LCV to LC1, offers linkages between health workers and that administration itself. The Uganda government provides funds to run primary health care (PHC) activities from the district to sub-county level. Every health facility within the district benefits. Locally raised district revenue is utilized throughout all the principal socio-political levels – from the district level to the various villages – according to the priorities of each local council. This, even though it is a good strategy by government, does not help the people down at the community level because the health units that are supposed to cater for their medical needs are usually out of their reach. With a health care structure, such as that, it is imperative for the communities to play an important role in multi-disease prevention and control, using the CDI strategy, if they are to stay healthy and useful. Better still, taking such a strategic stance is something they find inescapable. It is well known, besides, that it is when community members are empowered that it becomes possible to have basic health services delivered to the communities by community members themselves. Here lies the only secret if our work is to satisfy the true spirit of the Alma Ata declaration on Primary Health Care – aiming to achieve health by all and for all.

In the more recent times, however, there have been, on top of the question raised by Homeida, claims that substantial numbers of women, in Kisoro's communities of Bitare, Muko and Kikobero, do not take ivermectin



*Some community members who attended participatory evaluation meetings*

for the treatment of onchocerciasis. Yet for CDTI to succeed, all the members of an affected community, regardless of gender, are supposed to take the drug, achieve coverage of at least 90% of ultimate treatment goal (UTG) and above, collectively make decisions on how to manage the program and also own it. Women in Uganda, moreover, comprise about 51% of the population, implying that they are the majority in the endemic communities. Also they have been culturally known to be the major health providers at family and community levels. Research experience has also shown that it is usually the individual women who encourage their family members to go for treatment against diseases. With the knowledge and understanding above in the back of this author's mind, the present study has been conducted to establish the veracity of the claim that many Kisoro women, who are physically or potentially vulnerable to onchocerciasis, use neither ivermectin nor any other modern medicaments.

### **Study Objectives**

1. To see if it is true that many women in the communities of Bitare, Muko and Kikobero, in Kisoro District, have not been receiving ivermectin treatment at all.
2. To find out whether women in these communities (Bitare, Muko and Kikobero) take other drugs besides ivermectin.
3. To ascertain community attitudes, and especially of women, towards treat-

ment with ivermectin.

4. To investigate whether there are socio-cultural and religious values that hinder both women and men from taking ivermectin

### **Methodology**

The three communities of Bitare, Muko and Kikobero, which are situated in two of Kisoro's sub-counties and of which we already read, were purposely selected as the specimen area for the study. The view that the trio is a stronghold of religious cults, whose members are not allowed to take any medicine, modern or local, influenced the choice.

Structured questionnaires, designed for households, were administered in sampled homesteads. Targeted members, especially adult male and female household heads, were asked to specify their personal attitude towards CDTI, to tell whether women in Kisoro receive treatment with ivermectin or not, to show if they ever use traditional or modern medicine to treat other diseases, and to describe their attitudes to the use of the latter prescriptions to cure these other ailments.

The researcher employed face-to-face interviews, using the questionnaires, which involved 180 community members, 90 of whom were female interviewees and 90 male respondents. Participatory evaluation meetings



(PEMs) were also held, one in each chosen community,<sup>3</sup> as another means of finding necessary evidence. Collectors of data for this study also had audiences with some key informants to supplement and/or clarify information already obtained by the other two methods. The interviews, PEMs and discussions with the informants all took place in March 2004.

Quantitative data were analyzed using SPSS and version 6.0 of the Epi-info software package (Centers for Disease Control and Prevention, Atlanta, GA). Qualitative data was analyzed using text base beta and frequencies. Analysis also took into account the words used by the respondents.

### Research Results

Under three subheads, corresponding word for word to the methods used to gather data for this investigation, we piece together the collected material. No rigorous juxtaposition and comparison of the findings are attempted, though, before the next major subtitle.

#### Face-to-face interviews

Results from these interviews revealed that the majority of the interviewees are knowledgeable about onchocerciasis and its control (95.6%); 96.7% know how it is treated; 97.2% have ever been treated with ivermectin (and of these 51.4% are females); 91.7% know what ivermectin tablets look like; and 92.2% stated that they will continue receiving and taking the drug, in the foreseeable future, provided the tablets remain accessible to them. Again, of those interviewed, 63.3% are Protestants, 26.1% are Catholics, 3.9% are followers of a religion indigenous to Kisoro, while 6.7% belong to such other religious camps as Islam, Christo wa Christo, and pentecostal Christian sects.

When questioned about the diseases common to their communities, mention was made of malaria, worms, diarrhea, scabies, measles, chest pain, asthma and stomach problems among others. Many respondents (98.9%)

said that whenever they fell sick they usually went to health units for treatment; 0.6% reported that they used herbal medicine during illnesses; and those who noted that they prayed to God for cure, when ill, constituted also 0.6%. An impressive number (99.4%) said that they ordinarily advise the sick to go to hospitals or smaller health centers for treatment.

When the female responses were analysed against those of males, there were significant differences in terms of their knowledge of how onchocerciasis is treated and in regard to whether they had ever received ivermectin tablets as medication against this disease ( $P < 0.001$ ). Womenfolk (98.9%) knew better than the men (94.4%); and bigger numbers of the women (100%), as opposed to the men (94.4%), had used the medicine. However, results regarding knowledge about onchocerciasis in general, whether an individual would continue receiving ivermectin treatment until onchocerciasis is eradicated, and whether someone takes modern medicine when sick, were not significantly different.

#### Participatory Evaluation Meetings

The people who attended participatory evaluation meetings (PEMs) were 25 in Bitare, 40 from Muko and 27 from Kikobero. Results from these PEMs revealed that almost all the community members – 72.5% in Muko, 100% in Bitare and a similar percentage for Kikobero – knew about onchocerciasis and its control and also about the kinds of people ineligible for ivermectin.

Of those who turned up for the PEMs, 6 (24%) in Bitare (and all these were men), 11 (27.5%) in Muko and 27 (100%) in Kikobero had attended health education meetings on the nature and control of onchocerciasis, which were organized by the community-directed health supervisors (CDHS) with the assistance of community-directed health workers (CDHWs) and community leaders in their kinship zones.

Nearly all of the PEM participants had received treatment with ivermectin dur-

ing the year 2003 – 92.6% of those from Bitare, 100% of those from Muko and also everyone (100%) from Kikobero. By the time of this study, in March 2004, and despite that mass treatment was still in progress in these communities, most people who attended the PEM sessions – 62.1% (Bitare), 100% (Muko) and 100% (Kikobero) – had received treatment with ivermectin for 2004. It was observed by the PEM members that ivermectin is given to them by trusted members of their communities whom they have selected from central places within their zones. There were, however, cases of people reported not to have been receiving ivermectin treatment. These are usually men who occasionally go out of their communities in search of work.

Diseases other than onchocerciasis, such as malaria, measles, ulcers, heart troubles, hearing difficulties, swelling of the legs, mental illness, backache, eye problems, tooth decay and asthma, were reported to be common in the Bitare, Muko and Kikobero communities. It is to lesser health units or hospitals that most people go for prescriptions, against these inconveniences, observed the PEM attendees. It was also mentioned that the local ambulance, engozi, is often the mode of transport for very sick people. However, it is common knowledge, among the three communities, that some herbs are used, mainly by older people, to treat different diseases, for instance tonsillitis and toothache. The younger generation, still, is generally known to shun such remedies. Treatment, using modern medicine, is nevertheless the preference of everyone, we are told.

PEM consultations reported the presence in Bitare of cult groups of a religious order. Pentecostal groups in Kikobero and Muko communities were likewise defined. According to the reporters, the “religious cults” of Kikobero and Muko have not negatively affected ivermectin treatment. The same observers, though, could not

<sup>3</sup> One of 25 people, another of 27 and still another of 40: See below for specifics.

maintain that those in Bitare are in the clear since “their members are not allowed to receive any form of treatment as God is said to be their only healer and savior”. However, the UTG of the treatment coverage of Bitare, for the years 2000 to 2003, which was submitted to the Kisoro DOC by the community’s CDHS, showed that 87%, 99%, 76%, and 93% of the people, respectively, have been receiving ivermectin treatment.

PEM sittings revealed that most of Bitare’s cult members, especially men, tend toward dissociating themselves from other people in their local areas of residence as well as from the community health programs of their neighborhoods. The sum total of men in an individual cult group, it was observed, is almost equal to that of its women members: Cult members, this author learnt, target men who, in turn, gain membership with their wives and children.<sup>4</sup> Bitare cultists habitually shy away from the use of modern and traditional drugs. Although these people do not publicly take any kind of medicine, it was discovered that the women, among them, do stealthily use some modern medications as one man narrates: “Women from the cult group usually take ivermectin and other drugs secretly without the knowledge of their husbands. They do this every year.” Understanding of a substantially similar nature was reechoed by some major informants: From Petero Ndyabarutsya, one of them, we are about to hear.

### Key Informants

Onchocerciasis, according to such key informants as Ndyabarutsya, was originally a mysterious disease among the affected communities of Kisoro, including those presently under study. People only came to understand what it really was during 1993 – at that time, samples of community members, whether looking unwell or appearing to be healthy, had to undergo skin snipping as well as a general body examination. They gradually got to know

more about the disease through health education by the health workers, community supervisors and the drug distributors.

Like most of the participators in the PEMs, the key informants had some knowledge of onchocerciasis – its signs and symptoms, its control, people who are not supposed to take ivermectin and how a dosage of the drug is determined. There are people in their communities, they reported, who, at first glance, do not take ivermectin, although the presumed exceptions are in the minority. Why some people, allegedly, are or were not taking the prescription was differently explained by the informants. The former, said the latter, (a) do not have worms; (b) see no need to continue with ivermectin after taking it for quite long; (c) get side effects whenever they take the drug; and (d) find no need to take ivermectin because, for those who are Barokore or affiliates of some other cult grouping, Jesus is their only healer.

Claims of nonuse of ivermectin, some of them at least, seem to stand because of our general ignorance of these people. For the Barokore, as an example, Ndyabarutsya describes them as a very tight-lipped group, an organization whose members do not interact closely with almost everyone else in their larger secular communities. It can be very difficult, he says, for that matter, to get some information about them or their activities. To a certain extent, however, the position of such fundamentalists as the Barokore, for those with a deep knowledge of Kisoro, is theoretical and easily falls apart, like a pack of cards, as comments Ndyabarutsya. “Among the Barokore it is the men who normally refuse to take ivermectin. The women usually take the drug covertly without informing their husbands. This is done year after year,” says this man, a very old member of the Bitare community, who commands considerable knowledge of the society. In other remarks, the point was stressed by Ndyabarutsya that heads of the Barokore sect always try to recruit into their body married males, who clearly

dominate their families, and that the converted male household head is regularly accompanied into the group by one’s spouse, and even one’s direct offspring.<sup>5</sup> A similar report, it may be recalled, was made by the many contributors to the PEM deliberations.

How the distribution of ivermectin is organized was also dwelt upon by the informants. The community leaders and distributors mobilize people to receive and take the drug after they have been informed of its arrival by community supervisors. The drug distributors are individuals in whom the community members have confidence: They are selected by show of hands in a general meeting, convened by community’s authorities, in a kinship zone. It was also reported by the informants that over and above onchocerciasis, there are other rampant diseases in their communities such as malaria, dental problems, worms, measles, backache troubles, eye distress, leg-swellings and ulcers. These adversities, they reported, usually cause people to visit health centers for treatment – facilities that are, however, long distances from the homes of many people,<sup>6</sup> and to most of whom fast modern means of mobility are unavailable. In spite of these impediments, most people, it was underscored; still walk to hospitals and health centers because they prefer taking modern medicine to traditional drugs: The former prescriptions, they think, are superior to herbs and other options of their kind.

### Discussion

With fieldwork discoveries before it, this stage of the inquiry draws critical attention to the treatment of onchocerciasis with ivermectin, management of diseases other than river blindness, the impact of religious cults upon disease treatment, and, how all this, most of all, reflects the nature and size of women involvement in disease control, especially that of onchocerciasis.

<sup>4</sup> The comparison was apparently not unaware of the factor of member widows and widowers in the cult groupings.

<sup>5</sup> See also Habomugisha and Agunyo (2004).

<sup>6</sup> Some of the health centers in the region are Kinanira and Rutaka

## **Onchocerciasis Treatment with Ivermectin**

Results, established by the study's three methods, tended to disclose this one crucial fact: Most members of the Bitare, Kikobero and Muko communities had been treated with ivermectin in the previous years, with women (51.4%) outnumbering their male counterparts in this exercise. While CDTI activities usually run from the start to the end of any one calendar year, with mass treatment lasting for nearly the first three months of the year, the majority of the expected beneficiaries, in the three areas, already had received the drug by the time of this research this year (15-21 March, 2004). Those still untreated promised that they would take it soon enough. Not only do some community members see and value the need to keep on using ivermectin so long as it continues to be on offer at no cost to the user. They also encourage others to receive the same treatment Moses N. Katarwa, Peace Habomugisha, and F.O. Richards, Jr. (2001): Community members, on the whole, do cherish the treatment program and only ask that the flow of the drug be maintained. Benefits of taking ivermectin are known enough by them: These include, among others, discharge of intestinal worms, and noticeable improvement in one's skin condition.

There were, nonetheless, persons who had not been treated in the past or who had skipped the medicine. Some such individuals had not even received treatment during the current year. Reasons why these people were missing out or had done so were readily forthcoming – earlier prolonged use of ivermectin and, thus, the appropriateness of discontinuing it, among several others. The fascinating thing is that for such cult communities as the Barokore, it is the men who normally refuse to take the medicine. Reports, which constitute a common ground between many of those that volunteered evidence for this exploration, however, leaves no doubt that the women members of this and other cult groups usually use ivermectin as

well as other modern medicaments from behind closed doors.

Data scrutiny also showed that more women than men knew how onchocerciasis is remedied and that, again, more of the former than the latter have ever been treated with ivermectin against the same disease. This agrees with some findings of such previous researchers as Moses N. Katarwa, Peace Habomugisha, Richard Ndyomugenyi and Stella Agunyo (2001): Because the women commonly stay within the communities, they are more likely to receive the drug and also to know more about onchocerciasis and its control than the men who usually move out of their communities in search of casual employment.

## **Where and When Other Diseases Strike**

Treatment of other illnesses and sicknesses, in Bitare, Kikobero and Muko – a topic on which we have already touched, but in passing – is popularly done with modern medicine. Traditional formulas, occasionally, are employed for cure of diseases. Community members believe, to mention this example, that local herbs and other domestic concoctions effectively treat diseases like dysentery, toothache and tonsillitis. Local herbal potions also are used to prepare patients for eventual commitment to modern health institutions like hospitals. The residents of the communities, where this work was researched, not surprisingly, showed neither remorse nor hostility towards modern medical practice. All but few of them said actually that they preferred it to traditional therapy, which they said was less effective than its modern alternative.

Bitare and Muko, two of the three communities, where the study was carried out, did not have village health committees. Although Kikobero has such a committee, it is more concerned with issues of sanitation and hygiene. It is therefore the duty of Kikobero's people, under their leaders, to deal with other health issues confronting their community. In circumstances where the situation is outside of their control, especially in times of epidemic outbreaks, the nature of the matter, including evidence of its inten-

sity, is usually reported to health workers at the nearest health unit.

## **Cult Groups – Impact upon Treatment**

The three communities of Bitare, Muko and Kikobero were selected because they had been identified as homes of prominent religious cults. Cult groups in Kikobero and Muko do not, however, ban their members from receiving medical treatment: As such they have no adverse effect on treatment of onchocerciasis. While the Muko and Kikobero cults are essentially fundamentalist (or “born again”), they are clearly more liberal than the Bitare cult group. Cult members in Muko and Kikobero, unlike their counterparts in Bitare, interact with the rest of the people in their communities and are also known not to be so secretive.

Members of the cult group in Bitare, we have seen, are not supposed to have any form of medical treatment – modern or otherwise – as God alone, through Jesus, it is said, is their healer. Because the women in this group apparently eat ivermectin clandestinely, that signals that it is more men than women, among the small community, reportedly composed of about equal numbers of mature males and adult females, who shun the drug.

## **Conclusion**

Numbers of CDTI women beneficiaries, in Kisoro, it may now be stated, are apparently in no way inferior to those of adult male users of the drug in the district. Public and NGO health workers, especially those with a stake in onchocerciasis control, will, however, in the cause of research principles, need to subject this stand to further testing as and when opportunity makes itself available while they are discharging their medical duties. The final responsibility for this work unquestionably rests with me. I cannot overlook some persons and institutions, though, because in ways big or small they have contributed significantly to this product, and for this they are entitled to acknowledgment. Mamoun Homeida made the comment on

ivermectin use among the women of Kisoro, without which we probably would not have thought of conducting the study. Leads were later given by him to this author in her bid to find the APOC-TCC document that portrays the women of Kisoro as woefully behind the district's men in ivermectin use. Generous monetary support has been given by The Carter Center Global 2000 and Uganda's Ministry of Health – for fieldwork as well as for writing and printing. Staff of The Carter Center Global 2000 Uganda, considered as a whole, have stood by the writer in moral and logistical terms. In Kisoro District, the health services sector timely gave the go-ahead for this study to be done there. Mr. Christopher Ruzaza, Kisoro's District Onchocerciasis Co-ordinator, and his force of community supervisors provided necessary company and made data collection such a great ease. Without the collaboration of the respondents in Kikobero, Muko and Bitare communities, it would have been singularly hard to successfully accomplish this work.

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**End**

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## A Heart and a Vision to Serve

Harriet Sengendo & Peace Habomugisha

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The East Ugandan district of Mbale, from 19<sup>th</sup> through 24<sup>th</sup> July, 2004, was the focus of Peace Habomugisha and Harriet Sengendo's out-of-office duties. One of Uganda's easternmost areas, the district is graced by Mount Elgon – its best known geographical landmark, which straddles the Uganda-Kenya boundary.

The entire time they were in the region, Habomugisha and Sengendo, specifically, spent working hours monitoring onchocerciasis activities there. They interacted with different people, beginning with the district officials down to the health workers and community members involved in CDTI work.

Edirisa Wangwanyi, a focal and vocal man with "a heart and a vision to serve his people" to combat onchocerciasis, was one of the people with whom we had considerable contact at the sub-county level. Another example of the individuals who were in close interaction with us was Alexander Webisa. This report's title applies to him equally well: He, too, wishes to spread among other persons living with onchocerciasis the news of its likely cure through ivermectin prescriptions.

Webisa was already elderly, Wangwanyi a much younger man, and both of them live in Mbale District's small town of Jewa in Bufumbo community. Sengendo, mainly by means of prearranged

questions and with Habomugisha as her guide, interviewed the duo on the subject of onchocerciasis. The conversation is in two parts: The first is devoted to Wangwanyi while the second attends to the other man.

Comments by Sengendo and Habomugisha, on specific faces of the Wangwanyi and Webisa answers, particularly what are highlights of some deficiencies and obstacles in the Bufumbo CDTI initiative, take us to the last full stop of this work. After so much in introductory notes, we give you the particulars of the interviews – *qsn*, all through to the bottom, symbolizes the word question; *ans* answer.

### Part I – Edirisa Wangwanyi

**Qsn: Edirisa, can you please tell me about yourself?**

**Ans:** I am an energetic young man, aged 47. I am married, with two wives and we are blessed with 16 children.

**Qsn: What roles have you been playing in the Bufumbo community?**

**Ans:** I started my working experience as a literacy instructor. Currently, I am a secretary for education, mobilization and information in the Local Council One (LC1).



For the past 8 years, besides, I have served in the combat against onchocerciasis – first as a CDD from 1995 until the year 2000 when I became a community supervisor. Last year (2003) I was promoted, becoming a focal person, at the sub-county level, in the crusade against the disease.

**Qsn: What were your duties as a CDD?**

**Ans:** I did many things. I participated in training my fellow CDDs in our work, especially how to calibrate the sticks that are used in determining the correct dosage of ivermectin. I also gave health education in my community whenever my supervisors were not around; and I used as well to distribute the drug.

**Qsn: What roles did you perform as a community supervisor?**

**Ans:** I used to: sensitize the CDDs of our area, collect ivermectin from the nearest health center and take it to the communities, supervise treatment exercises, encourage my fellow supervisors who had lost morale because of not being paid for their services, help CDDs to update community registers, to oversee data management in general, and to report to the sub-county focal person above me.

**Qsn: Now that you yourself are a focal person have your roles in CDTI changed?**

**Ans:** Not really. What I can only say is that my roles have increased. There are 26 communities under me; and I have to make sure that they do their work well.



*Edirisa Wangwany (left) being interviewed by Harriet Sengendo, looking on is Emuron Eria, the Health Inspector, Mbale district*

**Qsn: What do the people of the area say about ivermectin?**

**Ans:** Community members love the drug; actually to them it is a “wonder drug”.

**Qsn: Can you please clarify what you mean by a “wonder drug”?**

**Ans:** It is a “wonder drug” in the sense that apart from treating onchocerciasis it has other diverse benefits. According to their experiences, for example, it relieves women of menstrual pain; to men who are presumably impotent, the drug gives power to perform their sexual duties; and men, whose penises are blocked, become well when they take the drug. All the parents, moreover, want their children to have the drug because of its de-worming effect.

**Qsn: What are the problems you have encountered in the course of your work?**

**Ans:** Here are some of them: (a) our sub-county has not honored its pledges to support community supervisors, and this has made some lose morale for CDTI work;<sup>1</sup> (b) house to house distribution of ivermectin is a challenge to the CDDs and yet this is the method preferred by community members; and (c) when some distributors and community supervisors drop out of the local CDTI system – due to such things as separation in marriages, deaths, absence in order to undertake studies somewhere else, and transfers – we have to train other people to fill in the gap(s). Recruitment of replacements has been hard because, at times, we even fail to get money to buy pens and exercise books for their training.

**Qsn: Despite these problems, what do you feel about your current work?**

<sup>1</sup> It is the politicians at sub-county level who have let down CDTI by not financially supporting people they are expected to assist.



**Ans:** I enjoy it. I was given a bicycle by APOC, and this has eased the work. I am available to serve my people, with or without pay. When members of the community see me moving around with a calibrated stick, they call me “doctor” and ask for ivermectin tablets even when it is not yet time for distribution of the drug. A young man, who, for a long time, was troubled by worms in his body, for example, had tried all kinds of medicines, both modern and traditional. He had, however, failed to be cured. When he started taking ivermectin four years ago (2001), he became well. Such things make me feel happy and more encouraged to serve my people to become a better and a healthy society.

**Qsn: What message do you want to convey to the district and sub-county leaders?**

**Ans:** For the district leaders, I would be happy if they could focus on advocacy, especially at the grassroots level. This I believe would help the public to understand that CDTI is a voluntary program and that, as the people who are directly affected, they are the beneficiaries.

Turning to the sub-counties, I would like the leadership to deliver on their pledges and support community supervisors, not only now but for many years in the future. These health managers are an important link between health units and the communities. If this link is catered for, then CDTI, I have no doubt, will be sustained and onchocerciasis will be eliminated in Mbale District.

## **Part II – Mzee<sup>1</sup> Alexander Webisa**

**Qsn: Mzee, kindly tell me about yourself.**

**Ans:** Born in Mbale District’s Nabushere community, I am now 76 years old; and married with two sons. For 9 years, I have been living a lone, however. I left my wife and children in a forest reserve in Namatala community, also in the same district.

**Ans:** When I went to settle in the forest, I left no one behind, in Nabushere, to take care of my land and other property. As time went by, some other people started destroying my coffee and banana plantations. They also tilled my land to grow and raise their own crops. This situation forced me to return to Nabushere to take care of my wealth. I felt, and still do, moreover, that I had a strong at-



*Mzee Alexander Webisa*

**Qsn: You said that you were born in Nabushere, how come that your family is staying in Namatala?**

**Ans:** There was a time, years ago, when my family and I used to go to Namatala Forest Reserve to collect firewood. This was later to lead to another interest: I decided to settle there because the land was also fertile.

**Qsn: What made you leave Namatala Forest Reserve?**

tachment to the land where I was born and circumcised from compared to the forest reserve.

**Qsn: Then, why did you leave your family in the reserve?**

**Ans:** My wife did not want to come back. My children, in addition, were still young and, therefore, I decided to leave them with their mother.

<sup>1</sup> A word that attaches a degree of respect to the person so called: Such individuals are usually people of old age.

**Qsn: Are you still in touch with your family members in the forest?**

**Ans:** Yes; my children and my wife used to come and visit me once in a while. They would even bring me some firewood. For the last few years, however, my wife has not been checking on me because she is sick and very weak.

**Qsn: What is your wife suffering from?**

**Ans:** Given the description of her sickness, it seems she is suffering from onchocerciasis. Her whole body itches and she scratches herself most of the time. My younger son has also been complaining of problems with his eyes.

**Qsn: Since you are suspecting that your family members have been suffering from onchocerciasis, what plans do you have for them?**

**Ans:** I am planning to persuade them to come back to Nabushere to start getting treatment with ivermectin.

**Qsn: Mzee, one of your legs looks as if it is burnt; what happened to it?**

**Ans:** My leg did not get burnt and it does not itch or even pain. I have been told that its condition is one of the true signs of onchocerciasis. People here say that the leg has a “leopard skin”. My leg has been like this for the last two years.

**Qsn: Did you know that you had onchocerciasis when you were still in the forest reserve?**

**Ans:** No, not all. What I knew, all along, was that I was suffering

from the “disease of the forest”, an affliction whose exact name I did not know. I used to scratch myself with a stone until blood would come out.

**Qsn: Now that you know that you have onchocerciasis, are you taking ivermectin?**

**Ans:** Yes, I have been taking the drug for the last 4 years. When I took the first dosage of 4 tablets, I got severe side effects. My whole body did not only become swollen; it itched as well – so much so that I could not even sleep.

**Qsn: When you developed the side effects, what did you do?**

**Ans:** I went to Bufumbo Health Center and was given some tablets; and, all of a sudden, my body became normal.

**Qsn: What message do you have for the Mectizan Inc. Co., the USA manufacturer of ivermectin?**

**Ans:** I am very grateful for the drug and may God bless all those who have given us ivermectin. I am asking them to keep sending us this wonderful drug. Wherever I will go, I will spread the good news of the possible cure, by ivermectin, of onchocerciasis.

### **CDTI Shortfalls and Bottlenecks**

Awareness, in Bufumbo, of onchocerciasis – its symptoms, its causes, its huge potential as a hazard to human health, its treatment and prevention – is one factor which, according to Wangwanyi and Webisa, partly accounts for the successes there of CDTI work. For the casual as for the serious reader, by reading between the lines or otherwise, their responses are not without great insights into the negative impact on CDTI of limited or no awareness of the nature and

scope of the infliction.

Eight years or so after the formal inauguration in Mbale of CDTI (community-directed treatment with ivermectin), some few individuals, in Bufumbo, who show signs of being infected with onchocerciasis, have only most recently come to know that they suffer from the disease. Others, such as the wife and children of Webisa, it looks, are yet to realize that what torments them is this very disease.

Lack of concrete financial commitment toward the war on onchocerciasis, in sub-county budgets, is also a pointer to extensive public failure to recognize the deadliness of this disease. Ignorance of the disease, to smaller or larger extents, even among some of those it has badly scourged, is thus still very much entrenched. Little wonder that Wangwanyi, with a passion, calls for far-reaching advocacy to educate the populace more about the affliction and CDTI.

## Treatment Updates (Jul-Sept 2004)


### News Flash

#### July 2004

7<sup>th</sup> to 13<sup>th</sup>: A surveillance team made up of Stella Agunyo and others visited Kisoro District to monitor CDTI activities through face-to-face interviews with household heads, CDHS, community leaders, and CDHWs. The monitors also checked community registers, in randomly selected communities, in order to validate treatment records submitted by the DOC.

19<sup>th</sup> to 23<sup>rd</sup>: Peace Habomugisha together with Harriet Sengendo had to monitor mass treatment in two districts – Mbale and Sironko. The distribution chain of ivermectin, in both of them, was trailed – from the head stores of the individual district and all the way through the strata of the health care system to beneficiary village communities. Not only did both officers interact with some continuing users of ivermectin. They also, in each of the two regions, visited the District Director of Health Services (DDHS) as well as the health and political leaders at the sub-county and other sub-district levels. With the DDHS and the leaders, Habomugisha and Sengendo discussed issues pertaining to CDTI

work, mostly its sustainability and integration in the primary health care system and the socio-political structure.

#### August 2004

9<sup>th</sup> to 14<sup>th</sup>: Stella Agunyo was in Mbale and Sironko to observe and assess treatment with ivermectin, as well as to provide supervision and advice where necessary. She had some audiences with various stakeholders like health and political officials at the district and sub-district levels, and with them shared important notes on how CDTI can be further advanced in the area.

#### September 2004

11<sup>th</sup> to 25<sup>th</sup>: Stella Agunyo, assisted by some CDTI officers, monitored ivermectin treatment in Moyo and Nebbi districts. This was achieved by face-to-face interviews with household heads, CDHS, CDHW and leaders of communities. Agunyo also held talks with the District Director of Health Services, of Moyo as well as with that of Nebbi, about what is expected of these districts, and what they can achieve, to sustain CDTI within their bounds.

15<sup>th</sup> to 25<sup>th</sup>: Peace Habomugisha had the mission to go, observe and evaluate mass treatment in Kabale and Kasese, and to offer appropriate advice to administrators of the program. A physical check on the storage and distribution network of ivermectin, between the district health offices and the onchocerciasis endemic rural villages, was made by her. She also interacted with some CDHS, CDHW and community members to find out why in 2004, compared to previous years, treatment data had taken longer to be collected and reported to The Carter Center Global 2000 in Kampala. Support was drummed up by her for the much-vaunted recommendation that sub-counties, to guarantee sustainability of CDTI, provide financial support to CDHS and other aspects of the program. In addition, she met the District Director of Health Services of Kabale and his team, with whom she discussed her field findings. With them, a way forward, that is how the district could sustain CDTI activities by, among others, integrating them into other health and developmental programs, was charted.

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