

## **Palliative Care Annual Report: 2008**

### **Introduction:**

The Evangelical Lutheran Church in Tanzania hospital system has witnessed an amazing growth in the palliative care outreach in 2008. Many hospital based teams have matured beautifully this past year, while others have scaled up impressively, taking the opportunities provided by significant funding. A huge addition to the outreach has been networking with the local congregations to provide some basic services for the most vulnerable children (MVC) in the various communities. The addition of vehicles in 7 of our rural sites has further boosted overall services impressively.

Continuing to receive funds from the United States PEPFAR program was again made possible by partnering administratively with Foundation for Hospices in Sub-Saharan Africa (FHSSA, [www.fhssa.org](http://www.fhssa.org)). FHSSA remains the "primary agency" receiving the PEPFAR funds. ELCT is the implementing agency. At ELCT the project is referred to as "CHAT", which comes from the project title "Contunuum of Care of People Living with HIV/AIDS in Tanzania".

Specific areas to be covered with this report include a review of the state of PC in the ELCT, and Tanzania as a whole. This includes reports on Personnel, activities such as meetings and supervisory travel, funding, places of special emphasis (Selian, KCMC), advocacy efforts, Challenges, and a view to the future.

To Review the specific Objectives of the PC program at ELCT, as established in 2005:

1. Each hospital will have an active Palliative Care team
2. Year by year, growth in service delivery will be accomplished and measured
3. Supervisory/Supportive visits to the hospitals will be done at least annually
4. Access to, and use of, pain medications will improve year to year
5. Education opportunities will be developed, by way of
  - a. Supervisory visits
  - b. Periodic meetings/seminars
  - c. Trainings regionally by other PC programs
6. Building up Selian and Kilimanjaro Christian Medical Centre (KCMC) as educational centers, which is key for future training and long term sustainability
7. Being a part of the overall improvement of Palliative Care in Tanzania
8. Integrating effectively with ELCT congregational service outreach
9. Building Partnerships for Sustainability

### **Tanzania Status with Palliative Care:**

There still is no government policy regarding palliative care in place. The policy that is officially in place is from 1992, though a Draft revision is now under consideration. Dr. Twalib Ngoma of Ocean Road Cancer Institute (ORCI) continues to be our strongest advocate to the government in the area of Palliative Care. Dr. Msemu Diwani, also of ORCI, and the Chairperson of Tanzania Palliative Care Association (TPCA) is another strong and able advocate for all of us. Their efforts, slowly but steadily bearing fruit, continue to be

appreciated by all of us.

Formal education for PC is not yet present, although initiatives are through TPCA, with ORCI leading the way. We are quite hopeful – again - that this coming year will see significant improvement.

Oral morphine (which availability is one of the benchmarks for PC services in a country) remains available only via special permission from the Ministry of Health and then via the pharmacy at Ocean Road Cancer Institute. There was no increase in the number of institutions (2) outside of Dar es Salaam accessing this drug in 2007. However, a huge change in this arena has come about by the efforts of ORCI. A 2 week training for the 4 major “consultant hospitals” of Tanzania (KCMC in the North, Bugando in the West, Mbeya in the South, and Muhimbili in Dar es Salaam), was led by Dr. Msemu in September of this year. Each of these hospitals is now in the process of finalizing plans to obtain oral morphine. What does this mean practically? It means that our hospitals in the South (Matema, Itete, Ilembula, and others) will soon be able to access oral morphine via Mbeya, just a few hours away. Our hospitals in the West (Ndolage, Nyakahanga, Bunda) will likewise have quite a reasonable trip to Mwanza, instead of 2 to 3 days journey to Dar es Salaam. And at KCMC, it means the key building block for an education program will now be in place. This is huge!

**Tanzania Palliative Care Association (TPCA):** was formally registered as an NGO in February of 2006. The Chair for TPCA remains Dr. Msemu Diwani, a radiation oncologist working at ORCI. Board Members include Kristopher Hartwig (writer of this report), Dr. Mark Jacobson of Selian Lutheran Hospital, and Nurse Paulina Natema of Selian, and others from involved Palliative Care organizations around the country. Funding for TPCA finally became a reality in August of 2007, and there is now an established office in Dar es Salaam, with a full-time Coordinator. TPCA really took off this past year, with significant funding coming – again – from PEPFAR, by way of the African Palliative Care Association (APCA). It has been a big shift for all of us to have full-time staff assisting in the work of advocacy and now program activities including education. As we seek to find an able Program Manager for the PEPFAR funded activities, there is hope for even greater involvement in TPCA with on-the-ground palliative care activities, making us increasingly visible around the country.

**Africa Palliative Care Association (APCA):** continues to be the strong leader in Africa in all areas related to PC. Dr. Mark Jacobson remains as the Chair of the APCA Board, quite a representation for ELCT and Tanzania. APCA’s presence as a continent-wide advocate for palliative care somehow continues to grow. Tanzania remains one of APCA’s focus countries for development, for which we are all grateful. Details of trainings and various country involvements are available on their website: [www.apca.co.ug](http://www.apca.co.ug)

### **ELCT Palliative Care**

**Personnel:** Kristopher Hartwig (medical doctor in PC and Evangelical Lutheran Church in America (ELCA missionary from the US) and Berit Hofgren (nurse tutor and Church of Sweden missionary) continued full-time work throughout 2007. For training meetings, we have continued to co-opted Rev. Gabrieli Kimirei of Selian, so as to have a “complete” team when presenting to hospital teams. Although Berit Hofgren completed her contract with the Church of Sweden at the end of this year. She will be sorely missed, yet has left a legacy of

motivated and well-grounded nurses behind, so that we know her position will be filled in a variety of ways.

Due to funding through the US government/PEPFAR, we continue to have an extremely strong team managing the program aspects of CHAT. Dr. Paul Mmbando leads the way as Project Manager, with Mr. Mellow Msurri the Project Accountant. Their savvy, experience, and ongoing knowledge of each and every hospital site has been the real key to this year's programmatic successes. Additionally, Ms. Diana Kajagi joined the team in February, adding her diverse skills to data collection, accounting, and supportive supervision.

**Supervisory Visits:** these were accomplished as noted in the chart below. All sites were reached by driving except Nyakahanga and Ndolage. A look at the ELCT health website ([www.health.elct.org](http://www.health.elct.org)) – click on “hospitals” and from there click on “map” – will reveal why driving is not usual to the far west.

Not visited in 2007	Lugala
Visited once	Bulongwa, Ilula
Multiple visits	Selian, KCMC, Nkoaranga, Machame, Marangu, Gonja, Bumbuli, Ilembula, Bunda, Iambi, Haydom, Ndolage, Nyakahanga, Matema, Itete, Karatu

Reports of each particular hospital visit are available for review. For 2008 a typical visit was:

- 1 arriving in the afternoon and evening
- 2 meeting with hospital/pc team leadership for planning and review.
- 3 Using the entire next day, according to the place's business for that day:
  - participating with morning devotions
  - CHAT follow-up of reporting, accounting, medications, care
  - Meeting with local or diocese church leadership
  - teaching to the wider hospital staff, especially regarding the assessment and treatment of pain
  - meeting with the PC/home care group, and doing home visits with them if possible.
  - Finally, the end of the day is to meet again with hospital leadership.
  - Further travel usually would be the next morning.

CHAT visits tended to take longer, with the significant reporting, accounting, and coordinating with the area churches all necessary. Details of the particular hospitals are below.

The ELCT Palliative Care team has also served as a consultant for the Mennonite Central Committee and its work with the Kanisa la Mennonite Tanzania (KMT). The training of December 2007 was followed up this year with supervisory visits to Dodoma (one program) and Mara Region (three programs). Each program is developing slowly but well, with ELCT being the avenue for medication and some other programmatic support depending on each site's needs and capacity.

**Special Emphasis:**

Selian Lutheran Hospital continues to be a place of special emphasis. It has a full-time Hospice/Home Care staff (9), and remains the only institution utilizing oral morphine in Northern Tanzania. They serve over 2700 clients (see Selian Annual Report through their website: [www.selianlh.habari.co.tz](http://www.selianlh.habari.co.tz) ). In our CHAT program, Selian is officially our "model" site. In training the other ELCT hospital teams, Selian's team and experience is used heavily.

KCMC: This has been a continued year of development for Palliative Care at KCMC. Professor Shao, the CEO, and Dr. Mark Swai, Hospital Director, continue to be very supportive. The training for oral morphine, as noted earlier, was undertaken by September. At this time virtually all steps have been completed to ensure the advent of oral morphine availability. Meanwhile, through ongoing relationship with the Clinical Pastoral Education (CPE) program and its Head Rev. Lyimo, a new position has been developed that will be full-time for palliative care. A Pastor from the Northern Diocese has been assigned, and the salary support comes from ELCT/CHAT. The 4 month CPE training has been completed by Rev. Msanya, and negotiations are now ongoing as to developing further team members. Human resource constraints being what they are at KCMC and other institutions, finding even a part-time nurse to assist in this work is a real task.

**Meetings Reports:**

February: the "Phase 2" hospitals (6 of them) of CHAT met for 2 weeks in February. It was a well-received orientation, and we learned a lot from the 7 Phase 1 hospitals that had been trained in November of 2007. Unlike the Phase 1's, these programs are all beginning organized palliative care services for the very first time. This includes learning the procedures for training community volunteers, how to identify and assist clients, and how to work with the clinical aspects of the care.

May: the Phase 1 hospitals of CHAT met as we sorted out how to begin implementation of services for MVC. Under the guidance of Dr. Mmbando, we spent 5 days with the core palliative care teams and the respective District Pastors (administrative leaders for the catchment areas of these programs). There was a mix of excitement and skepticism with this: how wonderful to initiate such tangible, valued assistances, but can we really do it?

September: Phase 2 hospitals now gathered to also learn the MVC aspects of CHAT. This time it seemed simpler, as we had seen the successes from the first Phase, as well as learning from some of their challenges.

December: All 13 CHAT hospital teams gathered with for 5 more days or further integrating MVC services into the program. This time there was significant input from the Ministry of Social Welfare, and other external advisors (Family Health International, USAID). Our start of services from May impressed our donors enough that Dr. Mmbando, through a variety of meetings, was able to get this very valuable input for our teams, and further give us learning and credibility as a recognized high-quality deliverer of care.

**Trainings:**

February: Dr. L.J. Mwakilule of Matema and Mrs. Joyce Mtinda of Iambi embarked on an 18 month Distance Learning Diploma in Palliative Care, out of Kampala, Uganda and Makerere University. These are our first ELCT health professionals to get such an opportunity. Thanks to Church of Sweden connections who have made this possible.

June: Mrs. Berit Hofgren and Dr. Kristopher Hartwig arranged a 2 day intensive on-site training at Karatu Lutheran Hospital. A non-CHAT site with many challenges in getting home care and palliative care services going in recent years, this was requested by leadership and was also something we at ELCT have hoped to “package” as a possible tool for better involving health professionals of the hospital in the palliative care efforts. 45 staff were each given a 6 hour orientation to palliative care.

September: TPCA funded a training for Tanzania Northern Zone stakeholders that was led by Selian. We at ELCT helped with the teaching and it was a good time to reconnect with area government leaders in the health sector.

October: Hofgren, Hartwig, and Rev. Kimirei were 3 days at Haydom Lutheran Hospital, giving them the training that was offered to Karatu. Over 100 staff attended, including many students from the Nursing School. Subsequent reports are that cooperation and referrals with the team have improved immensely.

**Hospital Reports, in brief:**

Phase 1 hospitals of CHAT are all on a similar level, with variation in number of volunteers trained and clients being served. Each (except Bunda) has a Toyota Landcruiser Hardtop which arrived in early March to great publicity and appreciation: Volunteer trainings finished by February, and some hospitals have already trained a second group (Bunda, Ilembula). Others will train another 15 to 20 volunteers by early 2009.

Machame, Marangu, Gonja, Bumbuli, Ilembula, Bunda, Iambi.

Phase 2 hospitals did not get vehicles initially, rather motorcycles and a travel stipend. Itete in particular suffers from not having a center for anti-retroviral prescribing, thus when a vehicle through other resources became available it was given first priority. Haydom, with the most vast geographic coverage, is also due for a vehicle soon, with the purchase done in October but clearances still underway. The hospitals:

Matema, Itete, Haydom, Nkoaranga, Ndolage, Nyakahanga.

There are 4 non-CHAT hospitals: Bulongwa, Lugala, Ilula, Karatu. Karatu and Ilula are making strides and have small but active teams in place. We look to support these sites as much as their capacity and leadership allow. Bulongwa and Lugala get medication support and

we continue to liaise with their leaderships, waiting for the right time to increase activities.

Please see the Appendix

**Funding Partners for ELCT:**

This year has seen a steady increase in support. Much of it is from the CHAT program, but as noted below support is diverse.

ELCT has become a funding partner at the local level. This is a special and exciting development. When teams do mobile outreaches into distant communities, typically it is a church doing the hosting, providing not only the venue but also the food for the many people who gather. Likewise for the delivery of MVC services the church does much of the logistic work on its own, easing the burden from our hospital teams.

ELCA, by supporting Hartwig, and Church of Sweden by supporting Hofgren, remain key supporters.

ELCA churches also contributed significantly, helping particularly with the Dodoma training funding and with the buying of several thousand dollars worth of medications for our various hospitals.

Mennonite Central Committee continues to supply key support for Hartwig's presence, and in addition funded the program developments as noted above.

FHSSA is our partner in working with the US government (see next section). Additionally, their partnership program gives us increasing exposure. Two years ago we had only one partnership, in 2007 four distinct partnerships. In 2008 four new partnerships were approved (A lot of thanks to Alex Shade of FHSSA, whose work is bearing fruit with these linkages)! On a visit to the U.S. for other business, Hartwig was able to visit the Colorado State Hospice meeting, and speak to over 300 attendees regarding the value and nature of such relationship. This will hopefully push things to develop even further.

Partnerships are:

Iambi - Vermont

Marangu - Kansas

Bumbuli - Colorado (Boulder)

Machame - Colorado (Montezuma)

Ilembula – Colorado (Grand Junction)

Bunda – Kansas

Nyakahanga – Michigan

Gonja – Connecticut

Haydom - Connecticut

## **CHAT**

"Contunuum of Care of People Living with HIV/AIDS in Tanzania", or "CHAT", is a huge partnership for ELCT. FHSSA has been providing assistance and program leadership from the beginning. In essence, CHAT is meant to scale up ELCT Palliative Care, using Selian as a model. It is a 3 year program, and we are just finishing year 2. Here are some of the key elements:

- Full-time Nursing leadership, and an Assistant, at each participating hospital
- Part-time clinician and hospital leadership involvement
- Training of community volunteers: 30 to be trained at each site, closely following the NACP Home Based Care training guidelines
- Special care and attention for orphans and vulnerable children
- Medicine provision - tramadol remains the strongest (and most expensive) pain drug in rural sites like ours
- Transportation provision (a vehicle for 6 sites, motorcycles and a vehicle lease fund for 6 other sites).
- Church involvement by actively training area parishes to be involved in the care and service provision
- Communication provision: computers, facilitating internet access
- Education: building up Selian and KCMC as training sites, Selian for community palliative care, KCMC for inpatient, intensive PC
- Quality and Data Provision: through the involvement and assistance of APCA, to have ongoing help in managing data, doing quality assessments, and evaluating information. We are using a tool called the "African Palliative Care Palliative Outcome Scale" which is proving very interesting and profitable in our training, follow-up, and quality assurance work.

We are very grateful to the U.S. government and PEPFAR, including its "New Partners Initiative" under which a Faith-Based Organization such as ELCT can be encouraged and enabled to provide significant resources to rural communities. Further information about CHAT can be obtained through the FHSSA website.

### **Church Advocacy:**

Ongoing visits to the hospitals are the primary form of advocacy, to hospital leadership particularly. Letters and fund transfers to hospital leadership are routinely copied to Diocese leadership. The CHAT program's Stakeholders Meeting was an excellent forum for sharing information in 2007, and we continue to build on that. Diocese visits are undertaken along with hospital visits when possible. In particular, the MVC work is "owned" by the church, and the experience has largely been very, very positive for the local congregations.

### **National Advocacy Work:**

Involvement with the TPCA as member of the Board meant several travels to Dar es Salaam, to interact with other key Committee members and particularly Ocean Road Cancer Institute. We continue to look to TPCA to be a national leader in setting standards, and in providing guidance

in the area of education and curriculum development. Additional networking trips included meetings with USAID and with other providers of care for MVC.

### **Overall Challenges:**

- CHAT funding has changed the nature of resource challenges for us. To date 15 of our 19 Lutheran Hospitals are enrolled in the CHAT program. The other 4, for a variety of reasons, were not suitable for this particular funding. One challenge is ongoing negotiations with USAID regarding future funding. The other area that CHAT brings as a challenge is "food insecurity", or poverty. Food provision and Income Generating Activities are 2 areas not supported by the program, and the needs for assistance in those areas will be huge.
- The rapid pace of developing Palliative Care in light of this new funding. We have a broad, long-term focus at ELCT, which makes rapid change difficult.
- Lack of Tanzanian health professionals trained in Palliative Care. Although strong training programs are present in Nairobi and Kampala, only two people in the ELCT system have been able to start this chance. This is a barrier to developing long-term educational activities, especially via Selian and KCMC, and so far it has appeared that donors are not so interested in education of this sort. That remains true with this new funding initiative, although we foresee KCMC becoming a site for such training.
- Long-term sustainability: this issue is now more of a consideration as we look at major donor involvement. What about after the 3 years are up? Our challenge is to build relationships of support and financing – with government, local organizations, the community/church, and international partners – such that each individual program has its own way of sustaining.

### **Way Forward:**

- Utilizing full time missionary staff who are dedicated to this work continues to be a great opportunity, though now that number is down to one. There is every reason to believe that their steady work in building up programs and relationships will continue to improve access to holistic palliative care throughout our ELCT system and even the country as a whole.
- Having a strong team now with another Doctor, an Accountant, and an Administrative Assistant adds huge strengths to the program. We look to add a Nurse to fill the gap from Hofgren's departure by early 2009.
- Careful soliciting of donor funding from appropriate partners, so that our goals of doing strong church wide development are accomplished without compromising our spiritual care and educational aspects.
- Ongoing advocacy at all levels: hospitals, church leadership, government, wider PC community, and wider donor community, including building relationships between small hospital-based programs and potential partners internationally.
- Building up the possibility of Selian and KCMC to become educational centers for Palliative Care, as envisioned and now budgeted in this year's ongoing grant
- Utilizing the tremendously committed Palliative care team members at so many of our hospitals. It is remarkable to us how many experienced Nurses have taken a real career

shift and gone from volunteering to doing this work full-time. They, and their network of community volunteers and churches, are truly our way forward!

### **Thanks:**

To all of our partners in this work, who are many:

- To Berit Hofgren – her tireless and interested inputs, always helpful, have been so key to the development of these services and relationships. For three and a half years – Thanks and God Bless.
- Evangelical Lutheran Church in Tanzania, in particular the health department and supportive leadership therein
- Selian Lutheran Hospital, and its leadership – Dr. Mark Jacobson, Elizabeth Makule, Paulina Natema - providing ongoing challenges, vision, and a rich, complex service
- The many hospitals of the ELCT, their leaderships and their Diocesan leaderships as well
- The Palliative Care and Home Based Care teams in each site, who encourage us mightily by their strong efforts, volunteerism, and love for people. Actually we cannot say enough about this cadre. We ask a *lot* of them, and continue to learn from their varied innovations and visions.
- The Evangelical Lutheran Church in American – for enabling Hartwig's work this year, including the opportunities to be in the U.S. twice in 2008 for networking with ELCA churches and Partner Hospices.
- Church of Sweden
- The many congregations and individuals who have supported this work by visits, gifts, encouragement, and prayer
- FHSSA and its vigor as a partner to ELCT in PC advancement
- Phil DiSorbo at FHSSA, who works so hard as an advocate for us in many ways – even to that huge, huge assist of getting a Toyota Hardtop donated from Union College of New York. We sure hope you can keep it up.
- Shelley Smith at FHSSA, whose brisk understanding of on-the-ground realities continually pleases and amazes us. A perfect advocate for us to USAID and PEPFAR.
- TPCA, APCA, and the wider network in Africa of those who care deeply about effective and loving palliative care in this region
- The government of Tanzania, for its patient and deliberate approach to health care development including Palliative Care
- ORCI, and its ongoing leadership and mentorship for PC development in Tanzania
- The U.S. government, and its willingness to fund a "different" way of doing Home Based Care and Palliative Care. USAID of Tanzania has been a valuable partner including Susan Monaghan and David Delem.
- Links for developing services for children have met huge inputs from Elizabeth Lema at USAID, Charles Matiko at FHI, and the Ministry of Health and Social Welfare of Tanzania.
- To our ELCT CHAT team in Arusha – Paul Mmbando, Mellow Msurri, Berit Hofgren, Anna Mahenge, and Diana Kajagi – who continue to amaze not only by virtue of tremendous work outputs but also by being examples of a wonderful team in every way.

- To our PC teams at each site – continuing to show vigor, innovation, and learning – they are inspirations for so many.
- To our clients who encourage us so much by their appreciation and grace in very difficult circumstances

Lastly, we give thanks to God for the opportunity to serve, and pray for wisdom and discernment in future endeavors.

Kristopher Hartwig MD  
Palliative Care Coordinator, ELCT

#### Appendix A

<b>Hospital under the CHAT program</b>	<b>Patients (these numbers are under review)</b>
Bumbuli	201
Bunda	312
Gonja	325
Haydom	278
Iambi	197
Ilebula	360
Itete	144
Machame	717
Marangu	300
Matema	185
Ndolage	247
Nkoaranga	351
Nyakahanga	237
<b>TOTAL</b>	<b>3854</b>

The largest proportion of these patients have HIV. The second group is having Cancer and after that it is a big mix. Variation in numbers between sites depends especially on how many non-HIV and non-cancer clients they are counting. During 2009 we should be developing the capacity to show not only the numbers by diagnosis, but also to show gender and age groupings.

<b>Hospital (non CHAT)</b>	<b>Total Clients</b>	<b>Male</b>	<b>Fem</b>	<b>HIV</b>	<b>Cancer</b>	<b>Other</b>
Ilula	84	48	36	72	2	10
Karatu	58	14	44	29	6	23

Appendix B

Hospital	Services Rendered 2008				Total #
	Medication	Education	Beddings	Milk/Nutri	
Bumbuli	0	146	62	18	226
Bunda	0	68	47	34	149
Gonja	0	97	65	16	178
Iambi	0	55	30	10	95
Ilembula	0	79	12	12	109
Machame	0	122	32	26	180
Marangu	0	204	8	68	280
Itete	0	94	14	12	120
Nyakahanga	0	41	58	10	109
Nkoaranga	0	66	9	3	78
Matema	0	60	30	3	93
Ndolage	0	74	3	8	85
Haydom	0	0	0	0	0
<b>TOTAL</b>	<b>0</b>	<b>1045</b>	<b>437</b>	<b>220</b>	<b>1702</b>

Medication (aside from ARV) will be a service that takes shape from 2009. For other numbers, these services have just begun and are taking off. Haydom will be taking off in early 2009.