

About TICAH

TICAH was established in Kenya in July 2003 to bring people together to strengthen our understanding of the positive links between the attainment of health and cultural belief, practice, knowledge, celebration, ritual, and artistic expression. We currently have five main projects, five “fingers” of activity:

Listening To Those Who Live It: We design and support activist and advocacy projects to bring the voices and experiences of HIV-positive people into conversations about health, policy, and well-being. As part of this work, we collect treatment stories, death stories, herbal and nutritional self-care strategies for staying healthy, and paint body maps, beautiful renderings of our lives as positive women and men. Most of this work combines partners and projects in Asia and in Africa.

Responsive Policy: We work with policymakers and donors who shape global HIV/AIDS agendas and funding so that we together can support more inclusive, responsive, and healthy comprehensive AIDS care for children, women, and men affected by the epidemic.

Respectful Research: We help put together teams of scientists and researchers with herbalists and traditional healers to better understand indigenous healing practices, assess their effectiveness and uses, and make them more known and available.

Nurturing the Next Generation: We work with university-based graduate training programs to encourage a more thorough and informed engagement with traditional cultures and indigenous knowledge, particularly as they relate to health and development.

Learning from our Elders, Honoring Spirit:

We work with traditional elders and healers and groups which support them to meet together at sacred sites and to share our experience and knowledge, to learn from them, and to bring their blessings together to promote health for all for us.



Amina Riðhwani presents Barbara's body map in Toronto.

TICAH & Toronto

TICAH brought a large team with us to Toronto this year. Our time there was appropriately started by a series of serendipities which led Mary Ann and Tara to attend the International Indigenous Peoples' Satellite – Working Together on HIV/AIDS, a very inspiring event on Saturday, August 12, which showed us how creative, engaged, and active native people

continue to be in the face of this epidemic. We are so grateful to have been led there and to have been welcomed with such open hearts of exchange. We hope that these spirited connections will continue to shape our learning and our work. We thank the co-chairs, Art Zocole and LaVerne Monette, for putting together a day of honesty, celebration, sharing, and friendship.

Toronto was our first experience renting our own booth in the scientific exhibition hall. While we felt a little overwhelmed by the size differential and obvious resource gaps between us and the huge pharmaceutical firms giving away free cappuccinos, we did find that our little booth was an excellent way to meet people and to share our approach to treatment, care, activism, and advocacy. We were able to display several of our body maps and share the six publications we have produced, two of them in partnership with others. Yes, all this in less than three years!

We were busy in Toronto! In addition to our booth, we hosted a performance of our body maps in the Global Village on August 16 at which our partners Amina Ridhwani, Veena Shenoy, Hemalatha, Siriporn Yongpanichkul, Bongkot Luecha, Christine Oyaró, and Bishakha Datta joined Mary Ann Burris, Tara Fitzgerald, Hannah Burris, Patrick Kearney, Jennifer Glick, and Kisha Montgomery in preparations and on stage. We easily distributed all of the copies we brought of our new publication, *Our Positive Bodies: Mapping our Treatment, Sharing our Choices*, and were rewarded with gifts and invitations to share these compelling visual stories with others. We hope to exhibit the body maps at the World Social Forum in Nairobi in January 2007 and are working with Bishakha Datta on a possible video, music, and dance to accompany them.

Also in Toronto, we were excited to meet Jonathan Morgan of REPSSI, Devan Nambiar of CATIE, Larry Gurney of Mad About Art, and others who believe that there is truth in the stories of individuals and there is power and healing in the beauty of expression.

Jonathan's early work with body mapping in South Africa, and *Long Life*, the book he did with Bambanani Women's Group, had been an inspiration for our own adaptation of this empowering tool, so we were thrilled to meet him and others we hope to work with more in the coming year. TICAHealth has been working with Xavier Verhoest on using hero books with positive children, another idea pioneered by our South African colleagues. More on this as it unfolds.



Veena Shenoy presents body maps from India in Toronto.

Also in Toronto, we celebrated the chance to be with our colleagues at PROMETRA, who had a beautiful booth in the Global Village, and to spend time with the traditional healers who are PROMETRA founders and members. They are our teachers and our comrades in this work. It is always an honor to be welcomed by them as family. We were asked to help to document plant spirit knowledge and medicine by a wonderful Cameroonian healer, chief, and elder, and we have agreed to assist in this way.

TICAHealth also hosted a skills building session on August 17 to introduce our second new

publication, *Using Our Traditions: A Herbal and Nutritional Guide for Kenyan Families*. Our room was filled beyond capacity and we had enthusiastic participants from all corners of the world. Tara ran the session by sharing the same approach we used in Kenya to put together this beautiful volume of herbal and nutritional treatments—that is, we asked people to discuss what they themselves knew and used. It was a lively ninety minutes. We shared self-care strategies for treating thrush, diarrhoea, cough, and nausea. Among the new ideas we talked about were okra cooked with bicarbonate of soda or ash for oral thrush, mango tree bark tea or basil leaves or turmeric for diarrhoea, grapefruit seed extract for oral thrush, fennel seeds for nausea. After demonstrating how community groups can use this process to collect potential treatment and prevention strategies, we talked about how to assess their effectiveness and safety. We then distributed our Guide to great enthusiasm. To hear the recording of this session, check out the “Programme-at-a-Glance” at www.aids2006.org/PAG/PAG.aspx. Then find “Practical Nutritional and Herbal Self-care for AIDS-Infected Families” on the page and follow the link.

Stories of Health, Stories of Death

What does it mean to “die from AIDS”? What are the stories of our positive friends and loved ones who pass away from AIDS-related causes? What are the death stories of others? Even at an anecdotal level, what can we learn from them? Further, what kinds of statistical information do we have or should we have about AIDS deaths, particularly in Asia and Africa?

For three years, TICAHealth has been collecting and sharing stories about how positive women and men stay healthy, but now we believe we need to learn more about those who die. TICAHealth and our many partners in Asia and Africa want to learn from the lives and the deaths of those closest to the

epidemic. As part of our *Listening To Those Who Live It* project, we have been collecting and publishing treatment stories so that we can learn from the positive and negative experiences we have had with different kinds of care, and from the choices we are making each day to stay strong and healthy. Also as part of the Listening project, we have supported the painting of body maps which beautifully document these care choices and the contexts in which they are made, which share our hopes and dreams for ourselves as positive women and our ideas about the kinds of treatment we desire and deserve. We have also recently put together a herbal and nutritional guide which includes natural, accessible homecare strategies for fifty-two of the most common AIDS-related conditions, particularly those which affect children (See below.) We have interviewed care providers and are currently working on a video of traditional healers talking about HIV. As part of this active listening, we have begun to collect the stories of those who “die from AIDS” in Kenya, Thailand, and India where our earlier body mapping and treatment story work has taken place. We hope to expand this work as widely and as sensitively as possible.

We invite others to join us in this. We believe that the experiences, knowledge, desires, and circumstances of positive women, men, and children are not being listened to as they should be. When it comes to paying attention to the ways in which people die, to the circumstances of those deaths, and the feelings of family members about the care their loved ones had access to, this silence is all the more deafening and destructive. As we write this, over two million die in Africa each year and over half a million in Asia. How much do we really know about the circumstances of these people who have left us?

What do we learn when we listen to the lived realities of those closest to this epidemic? We learn what we are doing right and what we are doing wrong. We

learn about how our families, communities, clinics, and places of worship support us and how they fail us. We learn about the many ways HIV affects our health, our spirits, our work, and our intimate lives. Who was supporting her during her last days? What treatments was he using? What illnesses had she had? What were his care providers doing? Who are they? Was she alone? Was he able to eat? Did she have any food in her kitchen? What were the available care systems doing for him? Had she given up and let go or did she really want to stay alive? Nothing puts our attempts to save life and our failures to do so more starkly into focus than these stories. When we learn that this positive infant “failed to thrive,” what exactly does this mean? How was her condition, her home environment, her support system, part of the story of her death?

What does it mean to “die of hunger and neglect,” as did Fatuma, one of our friends from Mombasa, Kenya? How could this have happened? Fatuma had been positive for over ten years, until very recently doing well using herbal medicines and trying to eat well. Six months before her death, Fatuma went on ARVs. She quickly went into decline and her family abandoned her. She could not work, so she had nothing to eat. She died alone, her four children frightened to go near her and her mother-in-law refusing to take her in. Her care provider says Fatuma “died of hunger and neglect.” What does this really mean?

Then there is Eunice, using herbal medicines successfully for years. Eunice was happy, healthy, and strong one day, in a coma two days later, and dead the third day of no obvious cause. Or Emma, who at the time of her death was on TB drugs. Her chest pain and malaria were chronic, but there was no indication before her death of any new condition or infection. What happened? Her nurse believes she “died of malnutrition and stigma.” Or Njeri, who learned of her status during her pregnancy, five months after her marriage? Njeri’s husband emptied their matrimonial home as soon as he learned of

her status. All she had left was her wedding ring, not even a bed or stick of furniture was left. Her sisters came to care for her, but she quickly developed pneumonia, bedsores, and meningitis. She just told everyone who tried to help to “Leave me alone.”

Is there anything that could have been done to save these women? If so, what, exactly? How much of this is about the right medicines at the right times, and how much of it is about other kinds of support and care? What do our cultures have to offer? How do our death stories differ from community to community, from country to country? What can we learn from this? Can we say anything definitive about those who die within six months of initiating anti-retroviral therapy? Can we say anything about positive children and the ways they pass away in one community versus another community? One household versus another? What are the patterns we can see and what are the ways in which we might better anticipate or address them?

TICAH recently had a poster session in Toronto at the XVI International HIV/AIDS Conference. It was a simple poster with a black cloth casket which stretched down the center of the canvas. On one side, we placed quotations from the death stories and on the other side, we pasted quotations from medical journals about causes of AIDS deaths, which, as one article admits, “remain ill-defined.” Together, how do we find more clarity about this? We know that some AIDS service organizations are keeping records of AIDS deaths, and we ask that you let us know what you are learning from this, or invite us to work with you to develop ways to do so.

TICAH welcomes all of you to visit our website at www.ticahealth.org and download our death story questionnaire, or make up your own. Please share these with us at listening@ticahealth.org and help us to honor the passing of our friends, colleagues, and loved ones by finding the

lessons in their suffering and passing. Help us all to remember and to learn.

■ Africa-Asia Interaction on AIDS

This on-going inter-regional learning network, which includes members from community-based AIDS organizations in the Greater Mekong Region of Asia and Eastern Africa, met again in Toronto. Launched at the earlier XV International HIV/AIDS Conference in Bangkok in 2004, and supported by the Rockefeller Foundation, this group again took time to share our strategies and update each other on our work. In the two years since our first meeting, we have had several cross-visits and projects which have resulted in a strong sense of community and an unprecedented opportunity to compare our situations, our challenges, and our strategies with one another.



The Africa-Asia Interaction on AIDS team bonds after a busy day in Toronto.

The InterAction has ambitious plans to continue in this work. Together with conveners AHADI of Kenya and Raks Thai of Thailand and our other partners in the two regions, TICAHealth will work over the coming year to try to secure the resources to allow us to build on our first two years of exciting collaborative evaluation and exchange.

■ Research on Patient Choice

TICAHealth, with support from the Rockefeller Foundation, has embarked on several small research projects designed to learn all we can from the ways in which positive patients in Africa are choosing their treatments, how different systems of care are working together, and what health outcomes can be documented from different strategies of care. Most of this work is taking place in Kenya and Tanzania. Stay tuned! We will report on this in greater detail in our next Newsletter, and we invite anyone interested or who is doing related work to get in touch with us.

■ Our Positive Bodies, Ourselves

TICAHealth has convened positive women's collectives to begin work on our new project, *Our Positive Bodies, Ourselves*. Again, stay tuned! We are very excited about our collective effort to share stories of disclosure, sexual life, pleasure, health, and rights that come from the experiences of HIV-positive women. We are exploring parallel projects in Asia and the United States and with the Boston Women's Health Book Collective who pioneered the first *Our Bodies, Ourselves* over twenty years ago. We hope to work with partners in Tanzania who are translating and adapting *Our Bodies, Ourselves* into Kiswahili for use in Africa.

■ TICAHealth Publications

TICAHealth produced or co-produced six publications between 2004 and 2006:

A Journey of Connectedness: Workshop on Traditional Medicine and HIV/AIDS - This is the proceedings of a huge gathering we helped to organize with Prometra Uganda and Twaweza Communications before ICASA in 2003. The meeting included nearly 100 traditional healers from all over Africa, and a few from Asia and Native America.

Nine Lives: Treatment Stories of Positive People - This is a sampling of the treatment experiences we have collected from Asia and Africa. They include a wide range of approaches-- from ARVs to herbs to nutrition and all sorts of combinations used by positive people to stay healthy. We have found that they are an inspiration for positive people and for all of us involved in this work. (Available in English and Thai.)

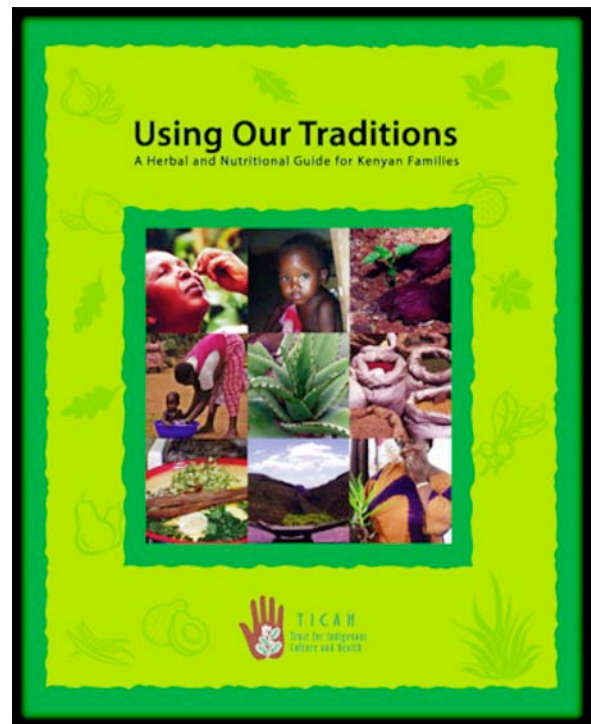
Unprecedented Conversations: Broadening Notions of AIDS Treatment and Care for Africa - this is the proceedings of a meeting we hosted in 2005, with Rockefeller support at their Bellagio Conference Center. We brought together folks from every stripe in the AIDS care world. In it, you see the outlines of the argument for why we need to have a different and more inclusive approach to treatment.

Closer To Home: Africa - Asia InterAction on AIDS - This is a report on an experimental inter-regional learning network around shared challenges at the community and household levels which include poverty, gender inequality, stigma, plus lack of appropriate and inaccessible care. It was launched in Bangkok in 2004 and continues to work together, facilitated by AHADI and Raks Thai Foundation.

Our Positive Bodies: Mapping Our Treatment, Sharing our Stories - This is a sampling of thirteen of the TICAH body maps done by positive women in India, Thailand, and Kenya which beautifully show our strategies for staying healthy and keeping hope alive.

Using Our Traditions: A Herbal and Nutritional Guide for Kenyan Families - We spent over two years collecting herbal and nutritional strategies for treating and preventing 52 of the most common opportunistic conditions (which also affect everyone, whether positive or negative). The Guide pays special attention to positive children and the ways to use diet and safe

and effective household remedies to deal with many of the conditions which plague those of us with weakened immune systems. It also contains recipes for low-cost nutritious meals and a plant index which, in addition to the 109 plant names in the book in English and Latin, has indexes in Kiswahili, Luo, Luhya, Maasai, Kikuyu, Giriama, Kipsigis, and Kamba.



To get copies of any of these, contact us.

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