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With thanks
to Dr. Charles Holt, Nalugo Susan and the Caring Hands Foundation
for housing me and helping me make the right connections
and to Kayamba John and his family
for taking me into their home and hometown.

Kasensero
Uganda

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To get to the fishing village of Kasensero, the beginning of it all, you take the Masaka road south from Kampala for approximately two hundred kilometers until you reach a fork in the road. The right branch leads to Tanzania, the other, to a thirty kilometer stretch of pockmarked dirt road ending at the shore of Lake Victoria.

The journey itself is one through living history. You pass through Lukaya and many similar towns that have sprung up to service the truck drivers who frequent this trans-African trade route. The stretch is referred to as the HIV highway for the exchanges between sex workers and drivers, drivers and their wives and so on that serve to spread the virus like a rippling effect from the source. Even as we passed through on our trip early one Sunday morning, we saw one massive eighteen-wheeler after another parked along the road, their drivers having spent the night in the hot zone.

Approximately one hundred kilometers south of the capital is the Masaka district, and along the way you can have your picture taken at the equatorial line. The line, like the borders of the neighboring east African nations, is symbolic in name only, otherwise practically insignificant and passive witness to the constant flow of human traffic across it.

Just south of Masaka is the district of Rakai. The name has been made familiar by the Rakai Project, a research collaborative between the Ministry of Health, Columbia and Johns Hopkins University. The district, which includes Kasensero and other fishing villages was the epicenter of the east African HIV epidemic. As awareness of the disease grew so did international interest in utilizing the entire population as an infectious disease cohort. An enormous amount of data was generated at Rakai, as every demographic detail, behavioral pattern and sexual habit of all consenting members of the community was studied and documented in exquisite detail, amassing a wealth of information from what was and still is a living laboratory. We stopped at the Project center, now renamed the Rakai Health Science Program, and were impressed by how over a hundred peer reviewed journal articles could have arisen from such basic facilities. Deserted on a weekend morning, we were greeted only by a group of parentless children waving across the street in their Sunday best.

Before arriving at Kasensero you can take a detour as we did to climb up to the surrounding hills where Idi Amin encamped his troops in the 1970s. It is a breathtaking and strategic vantage point, and in a 360 degree view incorporates the history of HIV as it descended upon the district from every direction.

Looking to the distance due west you can see the Democratic Republic of Congo, home to ZR59, the unidentified index patient from then Leopoldville, now Kinshasa, whose banked blood sampled from 1959 was the first documented case of seropositive HIV. Later, blood from the multiple ebola patients taken in 1976 in the DRC also tested positive. Tanzania is clearly visible just south of the campground. There is and has been free and constant movement across the border, including the march of Tanzanian troops into Uganda to depose of the despotic Amin in 1977. It is strongly suspected that the troops, along with their duty of liberation disseminated HIV in the region. Demarcating the border between Tanzania and Uganda is the winding Kagera river, the deepest and most power river in the world. It flows through Rwanda, from which thousands of Tutsi refugees fled into Uganda starting as early as the 1950s when the first killings began. Over the course of the ninety day genocide in 1994, over forty thousand bodies were dumped into the Kagera, and clogged the mouth of the
river at Lake Victoria. The national guard was called to clear the bodies, and as you drive back down the hill you will pass a mass grave site consecrated in August of 1994.

At the end of the road is a gated checkpoint, and beyond, Kasensero. The main road is narrow and lined by slat wood shacks topped by corrugated aluminum. The road ends at a tented cement platform, under which were constantly arguing in the car. The driver was of the Baganda tribe in central Uganda, the king's people, and the guide from Acholi in the west. Swapping between English, Luganda and the high pitched “eh” of dissent, they debated heatedly whether Buganda should secede from the country. With roots in the colonial days and the arbitrary unification of distinct peoples for the establishment of a national border, it was a tribal dilemma that was conspicuously out of place in Kasensero. On first glance, the village is a jumble of Tanzanians, Rwandans, and Ugandans from all parts of the country who came for the promise of money in the bounty of Lake Victoria. There is no sense of communal history, no common ancestry to stir either solidarity or contention. And only a handful of the residents are over forty years old. The population is mostly children and young adults, born after the end of the Amin years, and marked by the transience arisen from the high die off rate from AIDS and the immediate replenishment of new, migratory youth.

A friend from Rakai gave account of his earliest memories growing up during this period. It was scary, and one did not know her serostatus. It was a rare glimpse into the vanishedly rare opportunity to support themselves and their families. It was in this setting where in the late 1970s people began suffering from a strange illness causing cachexia, unremitting diarrhea and death. Their condition was termed Slim disease for the characteristic end stage wasting, and reports of the seemingly new and fatal illness drew medical officers from the ministry of health to the village in 1982. They confirmed the first diagnosis of HIV on the continent in a young woman who died the following year. Within the next several years the population was decimated by a third, with almost 200 deaths in the following year. Within the next several years the population was decimated by a third, with almost 200 deaths in the following year. Within the next several years the population was decimated by a third, with almost 200 deaths in the following year.

As dusk approaches, you can watch the crowds at the bars begin to disperse, and see the boys begin to slowly push boats, one by one, out into the pale waters of Lake Victoria. Like all others, continuing the way of life of Kasensero, making a living, skirting death.

How it Began

Mat Pho, 2007
Clinical Associate, Dept. of Medicine, University of Chicago (Writsana while a resident at Yale School of Medicine)

We met a woman whose seventeen year old daughter was charged with the responsibility of home schooling her six younger siblings. We watched as the five year old daughter recited multiplication tables and letters of the alphabet. The father had died of AIDS, and the mother did not know her serostatus. It was a rare glimpse into the heart of this community, epitomized by perseverance against unknowable odds.

We met the director of fisheries and agriculture, a man in his late fifties and a resident of Kasensero since the beginning of the epidemic. He led us by the hand into the village, walking through the narrow dirt roads between huts amongst the storekeepers, chapati makers, and families. We visited the mosque and the church. We met the chairman, a man with lion-like dignity who offered everything in his power to assist us in our efforts to aid his village. Outside of the clinic we encountered a theatre troupe rehearsing around a drum. They wore Lifeguard baseball caps, the brand of the country's most popular condom, and performed plays and dances in an effort to raise awareness of HIV. We saw many small children, playing in groups, being washed outdoors in plastic basins. There were more than three hundred AIDS orphans who were being cared for by extended families and neighbors. Many of the children dropped out of school because of their inability to pay the nominal fees.
"Kasensero is the end of the earth," said Dr. Majid Sadigh, trying to prepare me to travel to the little town in Uganda's southwest. Then he told me how his mentor, an icon of global health, had refused even to get out of the car when they had visited together.

I assumed that Majid was hyperbolizing. I had lived alone in the visiting physician's residence at the rural Kamuli Mission Hospital (one doctor, two hundred beds) in western Uganda, fumbled my way through language barriers, haggled for groceries and had better than survived, and so I figured I knew what he was talking about. But here, as it happens, I was wrong.

Superficially, Kasensero is not so different from many other small towns that I've seen in East Africa, distinguished only by its location on Lake Victoria. Concrete and wooden shacks line a single main street – which is alternately hot and dusty, and hot and muddy as the rain comes and goes – where a handful of vendors sell matches, biscuits and cellphone minutes, and bars draw in drinkers all day. There's little motor traffic, but a handful of boda bodas (motorcycles) are always on hand and ready to go. Periodically, cows take over the road. Off the main drag, wooden slat houses with corrugated roofs are packed tightly, making lines of shade where the trees have been cut.

When I arrived, after rolling some hours down the Masaka road and turning south of Kyotera, Town Chairman Kayamba John welcomed me with black tea and fruit as I have been welcomed in so many other places. For lunch, I ate the same matoke, posho and rice as anywhere else in Uganda, though with fish stew rather than beans or beef or goat. Like so many times before, I heard calls of, "mzungu, bye!" and "mzungu, you beat me a picture," and, colloquially, "mzungu, kuba tchfaunani!"

All this I had expected, but it's not what meets the eye or the ear in Kasensero that makes it, as Majid says, "the end of the world." Though these trappings do contribute, the condition is not seen so much seen or heard as felt heavy in the air when it seems, despite the flies buzzing and the clouds drifting, that time has become somehow immutable.

Kasensero is, I found, a place choked with cycles - constant comings and goings - of refugees and temporary laborers in and out as much as Victoria's waves on the beach. Every night, the fishing fleet casts off and every morning it trickles back to shore where wives and enterprising saleswomen wait to heap full plates for hungry men about to be paid in cash. At dawn, when it is still cool and as soon as wooden hulls slap the beach, all who are able grab onto the dhows and haul them up while tired pilots, sheepish or content, pull up tarps to reveal hulls full of success or empty with failure. Fish mongers swarm the gunwales to get the first look at the catch, handing out wads of bills to boat owners for the biggest animals. Then, as the sun burns through the morning clouds and fishermen take to the shade to shoot endless games of Parcheesi and pool, crews gather to sort nets, fix engines and prepare the boats to fish again at dusk. And so it goes, as Kurt Vonnegut might put it, day to day and year to year, week or weekend, punctuated only by the longer cycles of Church on Sunday or Mosque on Friday, episodes of rain and shine and life and death.

Fundamentally and at the center of these cyclic routines that shape life in town, Kasensero is defined by fishing. Officially, by label, it is not a town but instead Kasensero Landing Site, and the landscape is dominated by the Marine Group of Companies' canning plant on one side, the refrigerator truck loading dock in the middle, and the 500-boat fleet on the beach. Those few residents who do not work directly with the boats
Kayamba, “if you flip, you die.” It is normal for men to
where, without lifejackets or coast guard, says Chairman
Every night, pilots go alone out onto the lake
ing out). In Kasensero, concerns for the longer-term are
that Victoria could not take in what the town was put-
ergency struggles to keep tabs on the population (esti-
up to the water’s edge and accepting squalor. The gov-
reason to improve it, building shacks on the beach right
and it seems that the urge to leave is generally stronger.

“We have a big problem: it is AIDS,” says Chairman Kayamba who estimates that 42% of his
town’s population is infected with HIV. “The Rakai
AIDS has become as normal as hypertension in America.”

But this economy stands in stark contrast to the
rest of the country that is thoroughly dominated by
agriculture. Where elsewhere, even sewing and reaping
two times per year in the tropical soil, farmers must lay
down deep roots and wait to see a return on their invest-
ment, fishermen in Kasensero can bring in cash every
day. A pilot rarely owns his own boat and is instead gen-
erally staked by a wealthier man with a small fleet who
provides and maintains vessels and, in return, takes 70%
of the daily profits. Though there may be a motive to
stay and save money for a boat, there is no bank in town
and it seems that the urge to leave is generally stronger.

Few who are born in Kasensero stay there, and
instead many come from neighboring countries for a
handful of years at a time to make a living before, hope-
fully, going somewhere else to make a life. Thus, the
locals have minimal ties to the place and so have little
reason to improve it, building schools on the beach right
up to the water’s edge and accepting squatters. The gov-
ernment struggles to keep tabs on the population (esti-
National infection rate of 7.2%,1 estimates the population as between 8,000 and 15,000).

Hajji Mbirizi, the Kasensero’s LC III, told me that the
population is 10,714 and that 45% of the population has
HIV. Dr. Sadigb, after some years of involvement with
the town, believes that the infection rate is at saturation
for the population or about 60%. Any of these figures,
relative to the Ugandan national infection rate of 7.2%1,
are astronomical. And, regardless of the actual number,
the lived reality in Kasensero is that no one is unaffect-
ed by the virus, whether having it themselves, having
been orphaned because of it or having lost several family
members to it.

I talked with a number of families with kids in
who both parents were HIV+ and spent time at the
AIDS Clinic, is that Kasensero, “being a landing
site, anyone can come in or go out,” constantly tearing
out any roots that are laid down.

Slim Disease in Tanzania and Uganda, the rate of AIDS
infection in Kasensero would not slow. The seeming-
ly simple solutions of condoms and abstinence proved
too challenging for a town with many young men, drive-
by truckers and prostitutes, low levels of education and
high levels of civil apathy.

Long-time residents like Hajji Mbirizi, Mayor
Hajji Ssuuna and Chairman Kayamba are highly con-
cerned with the trend and steady toll of AIDS, but their
investments in the community – in schools, support
groups and efforts to draw internationally funded clinics
– have done little to stem the tide. The bottom line, says
Nyabire Sharon, a nurse midwife at the Health Center II
and the AIDS Clinic, is that Kasensero, “being a landing
site, any one can come in or go out,” constantly tearing
out any roots that are laid down.

Alec Jacobson
Early morning on the beach
Men and boys crowd the shore at dawn as the fleet returns, ready to haul in boats and restock nets.
A pilot organizes his boat after a night on the lake.
A pilot beaches his boat after emptying the night’s catch

A fish monger weighs a meager catch while the boat owner’s son looks on.
A fish monger offers cash up front for a load of fish

Men gamble in the shade out of the noon heat
Men untangle nets to prepare the fleet to fish again.
A group hauls a heavy dhow onto the beach

Main Street
A fisherman smokes marijuana to pass the time between fishing and fishing again.
Four fishermen relax in the room they share, waiting for sunset when they'll go back to the lake.

Shooting pool in a beach bar
A dancer at the Kapital Pub on a special "disco" night
Kayamba John, the elected Town Chairman, has lived his whole life in Kasensero. He owns 13 boats and the petrol station in town, and supports nine orphans in addition to his three own children. “We have a big problem here: it is AIDS,” he told me.

A nurse talks about the benefits of male circumcision at the AIDS Clinic. Men often come away from these courses believing that they will be immune to HIV if they are circumcised.
A drama group for orphans and widows watches a rehearsal.

Sseyondo James waits in line for ARVs. Both he and his wife tested positive for HIV in August of 2012. Together, they have two children.
A support group for women and orphans rehearses a drama
This page:
Posing for a portrait

Facing page:
A father poses with his son before putting him on a bus to boarding school in another town
Early morning on the beach. Burning trash and waiting for the rest of the fleet.
Begumisa Lojas works untangles nets for Chairman Kayamba John’s fleet. He was born in Kasensero and is raising his two sons there. Both he and his wife are HIV positive.
A catch of small nile perch

Men joke as they untangle fishing gear
Most of the fleet has returned and the beach is crowded when the sun breaks through the morning clouds.
Washing large nile perch before sending them into the Marine Group of Companies’ canning plant
Refrigerator trucks at the loading docks, parked and ready to take the day’s catch to cities around East Africa
Shooting pool at the New Mugamba Hotel bar