A tribute to AIDS campaigner Joep Lange by his son, Max.



The internationally respected AIDS specialist Joep Lange died on his way to a conference as a passenger on the ill-fated Malaysia Airlines Flight 17. He was the founder of PharmAccess, which initiated healthcare projects in Africa. His work has been continued since his death by the Joep Lange Institute. His son, Max Lange (1987), is now making a documentary for the institute about the impact of the mobile revolution in Kenya.

By Max Lange - reading time: 20 - 25 minutes

I'm riding in a black jeep on muddy roads through the slums of Nairobi. The roadsides are a hive of industry. Here, life is played out on the street. Those who aren't selling something are busy making things. Music blasts from speakers every few feet. I revel in the chaotic atmosphere. Everyone appears to have a cell phone. More than I had expected.

The reason I'm here has everything to do with my father's tragic death when Malaysia Airlines Flight 17 was shot down. I had paid scant attention to his work when he was alive: his research into HIV and AIDS and the projects he had set up in Africa. That changed when he died. I now make documentaries for the <u>Joep Lange Institute</u>. Together with my colleague, Dorte Hopmans, I'm here to make a film about the enormous impact of cell phones on everyday life in Africa, and the way <u>PharmAccess</u>, the organization my father established, has capitalized on this development. PharmAccess – the name says it all – aims to make healthcare available to even the poorest people.

My father often told me that Kenya was on the brink of a revolution in mobile telecommunications and healthcare. Together with PharmAccess, he developed M-TIBA, which allows Kenyans to use their cell phones to save money in case they ever get sick. Those who put aside a small sum via their M-TIBA account are rewarded with extra credit. And the great thing is that you cannot redeem that money for other uses. Sadly, my father did not live to see the launch of the project.

The cell phone as instrument of hope

We turn onto a smaller path, barely wide enough for the jeep. It brings us into a part of Nairobi that seems more like the countryside than the city. After around two hundred yards, we reach an improvised gate made from salvaged wood and sheet steel. It creaks open to reveal a thin, handsome man of around forty in a blue Chelsea shirt and jeans that are too big for him. He introduces himself as Sammy and invites us into his corrugated-iron house, no larger than my father's old garden shed. Sammy lives here with his two youngest children.

Dorte knows Sammy from when she lived in Nairobi. He makes leather belts and bags, and Dorte occasionally bought something from him. In recent years they have maintained sporadic contact via e-mail. Sammy speaks softly, with composure. We ask him what his cell phone means to him. He can't imagine life without it. His phone is an indispensible link in his leather business. He promotes his products via the Internet and sells them all over the world. He has customers in Germany, the US and Japan. The income from his business is barely enough to get by, but he tells us in all seriousness that his ambition is to be a decisive player in the global fashion industry. His cell phone is an instrument of hope.

A little later, his children arrive and immediately embrace him. Sammy strikes me as a dedicated and caring father. Where their mother is, I don't know.



Foto's: Dorte Hopmans

My father was busy saving the world

My own father played a less important role than my mother in raising my sisters and me. He was often away, and when he was at home he was unable to tear himself away from his work and was rarely able to relax. My mother devoted herself to raising her children; my father built his career and was the breadwinner. I understood later that this division of labor had been established early on. They married soon after meeting at the Academic Medical Center in Amsterdam, where my mother worked as a nurse, and soon started a family.

As I recall, my father was usually away, travelling in distant countries. To save the world, my mother joked. He didn't really want children. But my mother did. She told me that once, following an argument, she emptied a wastepaper basket over his head. After that, he changed his mind. She wanted eight children. She got five. I'm number two; the only son.

For me, in any case, his ideals meant that he was a father who was around too little.

My father encountered the new disease, AIDS, during his medical studies in the early 1980s. It was to become his life's work. My father was a highly motivated physician. I know several of his earliest patients; they all adored him and I can understand why. He was known for his even temperament, but also for his commitment, intelligence and sensitivity, and his enormous ambition and passion for his work. I would be happy to have him as my doctor. He took many risks, for example with dispensing new medicines, and I believe he did that with the right motivation: to help people.

I think back with mixed emotions on the role he played in my upbringing. For me, in any case, his ideals meant that he was a father who was around too little. I recall his long absences and the stress they caused: I was easily angered. But I also have warm memories: playing soccer together in the garden, running around the living room with my sisters to music from Fellini films, with him watching from the corner with a broad grin. Or his diversions – 'Have I ever told you the history of the potato?' – when the topic of conversation bored him. I believe he did his best to be a good, devoted father, but the pressure of work was too great and he had to sacrifice a great deal for it. He missed out on much of our childhood. When I had my swimming test, he was in Africa saving people's lives.

Kidnapped in Kinshasa

At home, he never really had an opportunity to talk about his work. We either didn't understand it or weren't interested. We didn't have a good mental image of what he was doing. And that, I learned only after his death, was a lot. Perhaps he didn't want to talk about it all the time and saw our home as the place to let go of it. I'm still amazed that someone who was so preoccupied with HIV and AIDS never told me about using condoms and the risks of sex. But he really wasn't the kind of man to initiate this kind of conversation. He wasn't very good at taking about personal things.

But he did tell us about dangerous situations he got into in Africa, such as the time he was almost kidnapped at Kinshasa airport. He could laugh about it; he wasn't scared. But all those stories took place far away from us.

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My mother preferred to keep her world small. Our life gravitated around a quiet village close to Amsterdam. We had very different problems to poor African AIDS patients and weren't easily able to identify with that part of my father's life. I once asked him: 'If you had to choose between saving the lives of all sick Africans or your own children, what would you choose?' To which he replied, without hesitation: 'My own children, of course.' That was quite a relief.

No interest in sitting at home among all those women

To the extent that it was possible for him, my father really did his best to be attentive to us. He occasionally took me with him when he did his patient rounds at the hospital, wearing his white doctor's coat. I could see that he commanded respect and then I really looked up to him. My sisters and I took it in turns to accompany him to conferences all over the world; I got a chance to visit Rome, Washington, Montreal and Bangkok. On those trips, he always made time to do things with us, no matter how busy he was.

But that didn't take away from how much we missed him at home. Looking back, I see now that his absence had negative consequences for me. I increasingly shut myself off from my family. I had no interest in sitting at home among all those women, so I hung out with a group of local boys and started smoking dope when I was twelve. I hated reading: one of my father's great loves.

My father made more time for his children after he and my mother separated, and our relationship improved in the years before his death. I lived in an apartment above his in Amsterdam and we frequently ate together. We grew closer through a shared love of film, music and books – I had later become addicted to reading. We both idolized Frank Zappa, whose music we would play during dinner, to the great annoyance of the others present.

Total shock

In the afternoon of Thursday July 17, 2014, I was taking care of the my father's new partner's mother, who was suffering from dementia. The television was on and there was a news flash: an airplane had crashed in Ukraine. I broke out in a sweat. The plane was heading to Kuala Lumpur and many of the passengers were Dutch. I had said goodbye to my father and his partner Jacqueline only a few hours earlier.

I was sure they had told me they were flying to Melbourne for the annual international AIDS conference with Malaysia Airlines via Kuala Lumpur. I immediately telephoned one of my father's friends, who tried to allay my fears. 'Don't be concerned; they were flying with KLM to Singapore. I'll call his secretary just to make sure.' Her words did nothing to reassure me. I grew more anxious with each second that passed, pacing to and fro. Ten long minutes later, the phone rang. First a long silence, and then: 'My dear, I'm so sorry. They were on board. I'm coming over.'

I went into total meltdown, hyperventilating. I went to the bathroom and threw cold water on my face. Then I lay on the floor and broke down in tears. After a few minutes, I called my girlfriend and asked her to come over. Then my best friend and my aunt. They all tried to calm me down, with little success.

'Is there something wrong with pop?' I heard that she imploded when I told her.

But I had to regain my composure, because it was I who had to inform my mother and sisters. Preferably via their partners, I decided, so that they could console them. I first called my two eldest sisters' boyfriends. Then my second youngest sister. She was at work, heard the distress in my voice and asked me: 'Is there something wrong with pop?' I heard that she imploded when I told her. Lastly, I called my mother's partner. A few minutes later, my mother called me back and began screaming. I tried to calm her down; no idea where I got the strength from: I was in total shock. I told her I would go to her place and had asked everyone else to do the same.

At my mother's, we all sat staring at each other, in tears. I will never get that image out of my head. As we sat there, I saw a guy in a truck on the other side of the street who seemed inconsolable. He was crying and banging his fists on the steering wheel. Had he also lost someone on that plane?

Closed casket

That evening, we stayed together. Everyone was a mess, but I gradually calmed down, no longer needed to cry. I rang a colleague to say that I wouldn't be coming to

work the next day. We ordered pizza and told funny stories about my father. I felt very different to how I imagined I would.

Later that night I went with my girlfriend and a few friends to Jazz Café Alto near the Leidseplein and drank a few beers. We slept at a friend's place. Crazily enough, I managed to sleep. At five in the morning, my phone rang. It was someone from Malaysia Airlines, confirming that my father had indeed been on board.

In the weeks that followed, I threw myself into settling my father's estate. It kept me occupied. I also had a lot of contact with the police and the airline, in particular to help identify the body. They asked us all sorts of personal questions, such as the location of birthmarks.

My father was found more than a month later. We were asked whether we wanted to see the body, but we were advised against it given the degree of decomposition, and opted for a closed casket at the funeral. Friends and family acquaintances told me that I was now the man of the family, and that's how it felt to me too. I felt responsible and took on a lot of duties.

As a family, we were never really angry. Anger is one way of dealing with grief, but it's not our way.

And then there was the whole media spectacle. My father was the best known of the victims. I received interview requests from TV and radio stations, but I turned them down. I felt I had nothing to add because I didn't know enough about his work. And I had no desire to add to the emotional outpourings on TV.

After a few days, I shut out all media coverage; I couldn't cope with the images of the debris. Since then, I have rarely opened a newspaper and I no longer watch television. And I attended only a single gathering for relatives of the victims. It wasn't really my kind of thing, though I was glad that Holland and the government responded so generously.

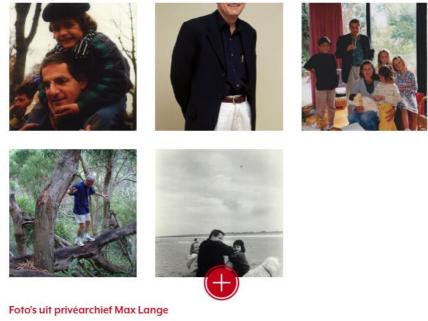
I noticed at that meeting that many other relatives were very angry: at the government, at Malaysia Airlines, at the Russians. As a family, we were never really angry. Anger is one way of dealing with grief, but it's not our way. I never concerned myself with the investigation into the disaster. Whether or not it was pro-Russian rebels who fired the rocket, my father is no longer here.

My wild life

I was able to take some comfort in the way my father was honored. A memorial service for him and Jacqueline, organized by colleagues, was attended by many

prominent scientists. People came from all over the world and Princess Mabel made a speech. This was when I first realized how important my father had been and how great the impact of his work was. This revelation and the countless expressions of sympathy helped me enormously during this period. My sisters and I occasionally felt uneasy with all the attention, indeed even a little ashamed with all these clever, ambitious and successful people around us, who seemed to have known our father very well. We didn't feel at home in this world and were afraid to be compared to him.

Things settled down after a month or two. I went back to work at the Hans Brinker Hostel in Amsterdam, where hundreds of young backpackers stay and where every night is a party. A totally different world. There I could shut myself away from all the fuss around the disaster and my father; I had had enough of all the attention and the hostel was the place to get away from it all. Most days I was there till deep into the night. It was the beginning of a long period of drinking and girls. I was enrolled in a bachelor's program in media, information and communications at the Amsterdam University of Applied Sciences, but rarely attended: it took me two years to write my thesis. At a certain point, I'd had enough. The hostel opened a branch in Lisbon. I could work there and get away from Amsterdam. My wild lifestyle continued in Portugal.



Shown: Max Lange's private photos

A photo of my father

In November 2016, more than two years after my father's death, two of my sisters and I travelled to Africa to visit several of the projects my father had worked on. The trip was organized by the Joep Lange Institute, which was established to continue my father's work. We spent three weeks travelling through Kenya, Tanzania and Uganda, visiting clinics where my father had set up health programs. Everywhere we went, we were given a warm welcome and everyone spoke about our father with great admiration. In a small hospital in Tanzania, the doctor asked for a photo of my father. When we gave it to him, he kissed it affectionately. My sisters began to cry and I was only just able to hold back the tears.

Through his work, my father helped countless vulnerable people in wretched circumstances. And yes, I began to understand why he was away from home so much.

I gradually realized that my father had had a far greater impact than I had ever imagined. He made an enormous contribution to the development of antiretroviral therapy, and his research into the prevention of transmission from mother to child saved many lives. Together with the organization he established, he made affordable medication available to millions of Africans in a period in which many were simply abandoned to their fate. Through his work, my father helped countless vulnerable people in wretched circumstances. And yes, I began to understand why he was away from home so much.

Doing my bit

During a dinner with one of my father's colleagues, I admitted that I was struggling with my own contribution and commitment. What had I been doing with my life the past few years other than enjoying myself? The things I had seen and heard during my trip to Africa made me understand this better. My father's colleague told me that everyone has to follow his or her passion: "That's what Joep did when he chose to study medicine. But he didn't think then that he was going to help huge numbers of people in Africa."

I knew he was right, but something kept gnawing at me. I didn't have to follow in my father's footsteps. Indeed, that was impossible: I didn't have the education for it. But I began to think about how I could do my bit for the campaign my father had fought for years.

And gradually, I became increasingly convinced that I wanted to contribute something.

In the months following the trip through East Africa with my sisters, I often thought about my father and what he had achieved there. The grief and sense of loss obviously resurfaced each time. I continued working in the hostel in Lisbon, but I had really calmed down, and began to read a lot about Africa and development aid. I also scoured the Internet for articles about and by my father. And gradually, I became increasingly convinced that I wanted to contribute something.

Early in 2017, I began a conversation with someone at the Joep Lange Institute. Wasn't there something I could do? The institute had initiated several new projects, including a research program with the world-famous behavioral economist, Dan Ariely, and a documentary about innovations in healthcare in Kenya. The institute now wanted to produce a follow-up film, and I thought to myself that perhaps there was a role for me here.

Since then, I've been to Kenya three times. After the second trip, I helped to write the script and prepare the recordings for the new documentary. During my most recent trip, I got to know Sammy and we began filming.

Revolutionary payment system

Sammy satisfies his thirst for knowledge through his cell phone. He searches the web for interesting articles and reads a great deal. We visit him again the morning after our first meeting. We arrive at around seven, just after the family has got up. I'm struck again by how considerate and kind he is to his children. He helps them get dressed and gives them a warm hug before they leave for school. I ask him where their mother is. He prefers not to say too much: he says she's still alive but has left him to care for the children.

We've arrived so early because we're going with him to the market, where he stocks up on leather. Once a week, he goes to the center of Nairobi in a matatu, a shared minibus taxi, to buy cowhides. This time, he comes with us in the jeep. The vast market area is a collection of chaotic stalls. There are fires everywhere and the stench of burning plastic. And the place is awash with car tires, which are recycled for making sandals and bags.

> Once they've agreed a price, they both pull their cell phones out of their pockets and begin typing furiously. The transaction is completed within a minute and we are on our way again.

We make our way through the narrow gaps between the stalls to the one where Sammy buys his leather. He casts a critical eye over the piles of tanned cowhide. 'This is the one,' he says to the vendor, approvingly rubbing his hand across the large piece of leather. 'Three thousand shillings,' the vendor replies decisively. At around \$30, Sammy thinks it's too expensive and they begin to haggle. Once they've agreed a price, they both pull their cell phones out of their pockets and begin typing furiously. The transaction is completed within a minute and we are on our way again. On the way home, Sammy explains how he paid: "I hardly use cash anymore now that you can pay everywhere with M-Pesa."

The introduction of this revolutionary payment system eleven years ago transformed people's lives in Kenya. Before M-Pesa, the majority of poor Kenyans were considered commercially uninteresting: you couldn't earn money off them. The mobile network operator Safaricom, M-Pesa's parent company, was the first to dare to target this group. It was a commercial success and led to the mobile revolution in Kenya. Today, almost every Kenyan has a cell phone with M-Pesa or shares one with friends or family. And you can pay with it everywhere.

In the afternoon, we accompany Sammy and his son, Eugene, to a clinic. His children have the usual health problems, and this boy looks especially weak. Sammy uses the app M-TIBA, which was co-developed by the organization that my father established. M-TIBA enables him to create a buffer in case of emergencies, and it also makes the relationship between patient and doctor more transparent. Patients can use the app to pay their bills with their cell phone, which prevents fraud, and they receive information about aftercare, such as medicine use. The information it provides gives doctors a better insight into patient behavior and enables care providers to work more efficiently.

Eugene doesn't have to wait long before the doctor examines him. Sammy pays the bill with M-TIBA. He has saved enough on the app, which is good because he spent nearly all his cash that morning on the leather.

Trade not aid

The following day, we visit the local PharmAccess office. The Kenyan branch of PharmAccess employs around sixty people, including many doctors, but also economists and people from other professions. Most of them wear suits and sit behind computers. When I'm introduced as Joep Lange's son, I'm the center of attention. They all seemed to have had great admiration for him.

PharmAccess is not development aid in the traditional sense: the free provision of food, shelter and medication, which has led to problems such as corruption and a culture of reliance. PharmAccess takes a different approach, summed up by the slogan 'trade not aid'. It works in partnership not only with the government, but also with the business community.

The healthcare programs with companies, including Heineken and Unilever, were initially met with criticism, but the critics fell silent, because it works. They believe here that the market can do more for healthcare than traditional aid. Led by my father, PharmAccess has set up healthcare programs with companies including Heineken and Unilever. This was initially met with criticism, especially from traditional NGOs. But my father paid little attention, and the critics have fallen silent, very simply because it works.

M-TIBA is also based on a public-private partnership. The app is partially funded by donor money, but users like Sammy have to pay part of the costs themselves. The clinics have an incentive to make profits, so it's in their interests to deliver good services. I am reminded of a statement by the economist and Nobel laureate, Angus Deaton: "If poverty is not a result of lack of resources or opportunities, but of poor institutions, poor government, and toxic politics, giving money to poor countries— particularly giving money to the governments of poor countries—is likely to perpetuate and prolong poverty, not eliminate it."

The African dream

We are following Sammy for our documentary about the mobile revolution in Kenya. We're working with the Kenyan filmmaker Timothy Mwaura, whom I meet for the first time in a bar in the center of Nairobi filled with hip young Kenyans. Tim tells me his story. He grew up in Korogocho, one of Nairobi's largest slums. His parents were very poor and he shared a bed with four brothers and sisters. His mother noticed that he was smart – smarter than the rest – and encouraged him to study. Tim bought his first camera at a young age. Although it was a very cheap model, he had to save up for years to afford it. He started his own production company and gradually worked his way up. He now films with equipment worth \$80,000 and employs a few people. 'I've realized the African dream,' he jokes.

The cell phone has given people a voice, a tool for controlling those in power.

Our documentary on the mobile revolution is about Sammy and the effects of M-TIBA on healthcare, but it is also about the influence this revolution has had on politics, and how it has given poor people security, solidarity and a voice. People share stories about corruption and political violence on social media, and that puts greater pressure on the government. Tim's soundman tells me that there used to be frequent police roadblocks in his neighborhood. 'Everyone they stopped had to pay a bribe'. He can't imagine that happening now. 'The cops are too scared that people will post photos or films of them on the Internet.' The cell phone has given people a voice, a tool for controlling those in power. The mobile revolution has also created a new sense of solidarity. During the riots around the last elections, many houses and shops went up in flames. A group of young Kenyans responded by starting a website through which people could offer a place to sleep to those who had lost their homes. As a result, hundreds of people were spared the indignity of sleeping on the streets. It was a great success.

Improving the world

My work in Kenya has changed my view of Africa enormously. There is a lot of misery there, but there are also positive developments, such as the mobile revolution. Kenya is leading the way in the development of new cell phone applications. What I have seen makes me more optimistic than I was before.

My life has also changed enormously in the recent period. I stopped working at the hostel, and I now live in the Portuguese countryside, where I'm building a sustainable camping site with two friends from Amsterdam. We do our best to live in an ecologically responsible manner. If you want to improve the world, I think that has to start with your personal life.

I'm also more at peace with the relationship I had with my father, and I have a greater understanding of why he was absent during my childhood. Above all, I'm now immensely proud of his achievements. My contribution to the Joep Lange Institute is a tribute to him.

Disclaimer: this is a translation of Max Lange's article for Dutch magazine *Vrij Nederland*, originally written in Dutch. All pictures are from the original article.