



# Our Story



***This story has been complied by Dr Samuel Guma, Co-Founder and Executive Director of Kawempe Home Care.***

## How We Began Our Journey

In July 2007, a group of devoted health workers saw there was a big need for medical assistance for people suffering and dying from AIDS in the poor slum community in Kawempe, on the outskirts of Kampala city in Uganda.

The members of the team had previously worked in organisations that provided holistic care to patients and their families with HIV/AIDS and cancer. Armed with a great deal of knowledge in care and support for patients with these diseases, the team set out on July 27<sup>th</sup> 2007 for the first home based HIV counselling and testing visit. A total of 12 people were tested, 5 were found positive and were enrolled into the program.

## The Team

The team had the equivalent of \$100 which was used to buy HIV test kits and a few tins

of the antibiotic, septrin used to prevent some HIV opportunistic infections. Each made their own personal contribution in the form of medicines, furniture, vehicles and personal finances for travel from their homes.



***The Founding members comprised of: Dr. Samuel Guma – Project Coordinator, Sarah Komugisha – Medical Manager, Gerever Niwagaba – Community and Social Support Manager, Anni Fjord was the Director, John Amanyire, Laboratory Technologist and Alicitidia Tusimemukama a Counsellor. Missing is finance consultant, Bruno Onzima who also supported the team. (2008)***

After a couple of weeks of providing care to the clients in the community, we realised that we needed more people skilled in project management so we asked Anni Fjord, a Danish nurse who some of us had

previously worked with to join us. She agreed and joined the team a few days later. Anni had many years of experience working with International non-governmental organisations and she also had many local and international contacts. She contacted them and was able to raise more funds to buy medicines, food for destitute patients, fuel for home visits, transport for patients to get antiretroviral therapy from nearby hospitals and HIV/AIDS care organisations. She also availed her four wheel drive vehicle for home visits.



***Our intrepid team sets off in their mobile clinic. (2007)***

Anni arranged the first team strategic planning meeting in August 2007 at the home of one of our first clients who is also a women's leader in the community. Developed were the organisation's vision, mission statement and objectives and the management team to lead the organisation.

## **Community Involvement**

As the weeks went by, the news about our services spread throughout the community. We were fortunate to meet one of the

women leaders in the community who welcomed us into her home and offered us space where we could keep our medical supplies and patient's files since we didn't have any office space and were operating as a mobile clinic. Each morning when we arrived at her home to pick up our supplies, we would find two or three people who would have come to seek help for their neighbour or relative dying with AIDS.

We were approached by members of the community who wanted to join us and provide care for people in their community. The pioneer community volunteers were Namulinda Zainah, Joyce Nakyazze, Maria Assumpta, Namuddu Joyce and Nakamatte Cissy (RIP). The number of patients joining our program rose by the day and this gave the team more courage and strength to tread along a path of an uncertain future to provide holistic care for the patients. We held the first training for community volunteers in 2008 and they were given basic skills in palliative care, medication adherence support, and counselling.



***Sarah treating a patient at home. (2009)***

## **Kasangati Outreach Clinic**

One of the first volunteers Joyce Nakyzaze, resided in Kasangati town approximately 14 km from our area of operation in Kawempe. She requested and pleaded that we make arrangements to conduct a HIV testing outreach in her community, since many of her friends and neighbours were dying from AIDS. The team agreed and on the last Friday of August 2007, we set out for the outreach clinic.



***Gerever speaks with patients at our first outreach clinic in Joyce's home. (2007)***

We found over 70 people waiting for us at Joyce's home. We got straight to work and began counselling and testing the clients, we diagnosed 41 people with HIV/AIDS and started them on treatment. Many of them were very sick with advanced AIDS and were in need of home based palliative care.



Joyce was a Godsend for the program, she provided her entire house i.e. sitting room, bedrooms, store etc. for the outreach clinic every Wednesday

for the next two years. So many people who were on their death bed were given a new opportunity for life and those that passed on did so in dignity, free of pain and suffering.

## **New Home**

After three months of operating as a road side and home based mobile clinic, we decided to look for a house to rent and thankfully we received our first grant as an organisation from Friends of Reach out (FORO) of \$7,000. The premises we found was a small three bedroom semi-finished house which became our office and clinic. We now had a base where we could treat the patients, keep our medicines and files and conduct training for the staff and community volunteers.



***Dispensing medicine. (2012)***

We didn't have any furniture for the new house so Gerever Niwagaba donated chairs and tables which he had bought to start up a restaurant business near his home. Anni also mobilised furniture from her home and from her friends.

Dr. Margrethe Juncker one of the members of FORO, was instrumental in helping us get our grant. I met her in 2001 while working



at Hospice Africa Uganda where she was volunteering to provide palliative care for HIV/AIDS and cancer patients. During one of the Hospice home visits, she visited a slum community inhabited by people who had fled their villages due to the war in the northern part of the country which had been started by Joseph Kony of the Lord's Resistance Army (LRA). She was touched by the plight of the people and so teamed up with the area Parish Priest Father Joseph Archeti (RIP) to set up an organisation Reachout Mbuya HIV/AIDS Initiative.



***KHC recognises the wonderful support Dr. Margrethe Juncker has provided us and continues to do so. (2013)***

During the start-up of this organisation I would join her team during my free time and volunteer to care for the patients. In 2005 I joined her organisation and worked with her for a couple of years. She therefore knew that we were committed to the cause and she advocated for our first grant from FORO.

### **Strategic Partnerships**

As the number of patients increased so did the need for resources i.e. medicines to treat opportunistic infections, food for

destitute patients, antiretroviral medications, transport costs for referral of patients etc. We decided to approach local HIV/AIDS service organisations and tap into their resources. The first step was a visit to the Ministry of Health AIDS control program where we met Dr. Elizabeth Namagala who received us warmly. She visited KHC and conducted an assessment.

In May 2008, KHC was accredited as an antiretroviral therapy treatment clinic so we began receiving medicines and HIV test kits from the Ministry of Health. The AIDS Information Center (AIC) also agreed to give KHC HIV test kits, condoms and antibiotics. Dr. Raymond Byaruhanga the Executive Director provided moral and material support for KHC. We also visited the Joint Clinical Research Center (JCRC) one of the first organisations to start antiretroviral treatment in Africa and KHC was included in their TREAT (The Regional Expansion of Antiretroviral Therapy) project. We were then able to get antiretroviral medicines which also enabled our bedridden patients to access medicines at home.

The JCRC team, Dr. Victor Musiime, Mr. Michael Kabugo, Dr. Cissy Kityo and Prof. Peter Mugenyi were very supportive. This support provided a very strong foundation for the HIV/AIDS care and support services. The country manager of Glaxosmithkline Uganda Mr. Nathan Wasolo also supported us with tins of antibiotics.

### **Outstanding Personalities**

During the inception of the organisation, the team faced many challenges and hurdles. However during this time a number of

people came to our aid and provided a lot of moral, technical and financial support.



These included Mr. Aloysius Byaruhanga an audit and procurement specialist currently Deputy Director Procurement

Audit and Investigations Department with the Regulatory Authority (PPDA) of all government Procurements and Disposals. He provided technical and financial support that greatly contributed to the start-up of the organisation and later became our Chairman of the Board of Directors. Dr. Victor Musiime a paediatrician with the JCRC, provided technical advice in the design of the program, he also supported the clients including children to access the much needed antiretroviral therapy from JCRC. Jennifer Kanjogera provided technical advice in management and also gave donations of clothes and finance for the children's program. Dan Wegulo an advocate of the high court provided pro bono legal services and helped us draft our constitution and supported us to register as a private non-profit organisation.

This group became board members of the new organisation.

### **We Knew It Wouldn't Be Easy!**

The first year at KHC was both exciting and scary due to uncertainty of what the future had in store for us. For two months the members of the team worked without any salary. Those who had means of getting

themselves to work used public transport, while those who didn't would walk every morning from their homes to the agreed meeting point at a petrol station in the community we were serving.

There was however a very strong aura of joy and the members would share whatever we had i.e. food, pocket money etc.



***Medical staff take local transport to go to the outreach clinic. (2008)***

The challenge in raising funds to cater for the clients' needs, the support for the team i.e. food, transport and monthly stipend etc. was a major cause for concern for the leaders. Despite all this more and more people came looking for assistance for their loved ones who were dying with AIDS.

Thankfully the team was totally committed and they kept coming to work without complaining and were thankful for whatever they received.

What kept us going was we believed that God was guiding us to do something positive to help people who were in pain and suffering and who medical assistance was not previously available to them.



### ***Home visit. (2011)***

I had to travel upcountry on one of the days of the outreach clinic in Kasangati. At that time Sarah and I were the only health workers who could treat the patients and she was at the time 6 months pregnant. I informed her about the need to travel and my worry about how the clinic would run in my absence. Her response was "don't worry I will manage". That day over 50 patients turned up for care and she saw all of them by herself all day until 4pm. The other members of the team were amazed at how she had managed to see all the patients and they cheered and thanked her for the job well done.

### **Anni's Departure**



In May 2008, Anni told us she was leaving Uganda and returning to Denmark with her family. The news brought the team's spirits down and we all started wondering how the organisation would continue without her. I personally had some serious thoughts about what the future held for us and our patients

but knew that the journey we started couldn't be abandoned. I then rallied the team together and I assured them that if we kept steadfast and committed to the cause, we would make it. I met with Anni and we shared ideas of how we could carry KHC forward, she advised that we invite another friend Mr. Chris Hodun a brother in the Catholic Church to join the team. Anni then arranged a team retreat at Kazi sailing club for team building and planning for the future. The new management team was then named with Dr. Samuel Guma as the Executive Director. Chris Hodun, Operations Director, Gerever Niwagaba Administrator, Sarah Komugisha the Medical Manager and Elias Tumwine the Accountant. Anni bid the team farewell and promised to continue mobilizing funds for KHC.



Anni also started up the Beads for Education project and after she left she became the first ambassador to promote and sell the

beautiful recycled paper bead necklaces in Denmark.

She also set up *Culture Without Borders* which has been providing funds for the orphans and vulnerable children programs and welfare of the KHC staff.

### **Hope for the Future**

In the second half of 2008, the team put in a lot of work to mobilise resources for the organisation. A Tuberculosis program

funded by USAID, TB CAP provided KHC with a three year sub grant to do community based DOT in the community. Special thanks to Dr. Anna Nakanwagi the TB CAP Chief of Party who enabled us to take up this project, despite KHC being a young organisation.

Hope for Children International (UK) for the past 6 years has provided much needed support for the Kasangati outreach clinic.

The US embassy small grants project provided a three grant for care for the PLHA, orphans and vulnerable children and adherence support of patients using mobile phone technology. Special thanks to Ms Connie Hansen for the support that she gave KHC during this period.

The Friends of Reach Out (USA) continued to provide funds annually. The Ministry of Health and the JCRC TREAT project continued to provide antiretroviral therapy medicine and other support for our work.

This support set KHC along a path to become an established organisation with the capacity to provide care to over three thousand patients to date.

## **The Stars of KHC**

Throughout the journey of KHC a number of personalities have come along and have made major contributions that have enabled us to progress.

This is their story;

✚ Anni Fjord has been very helpful over the years and is still very involved. She has been mobilising funds for the orphans and vulnerable children's

program with sales of the KHC beads jewellery and funds for staff welfare. Anni visits KHC at least every two years and we are always delighted to discuss issues share ideas, and have fun.

✚ Dr. Margrethe Juncker has since the beginning provided lots of encouragement, technical and financial support. The funding she helped secure from FORO from 2007 to 2013 went a long way to ensure the longevity of the organisation.

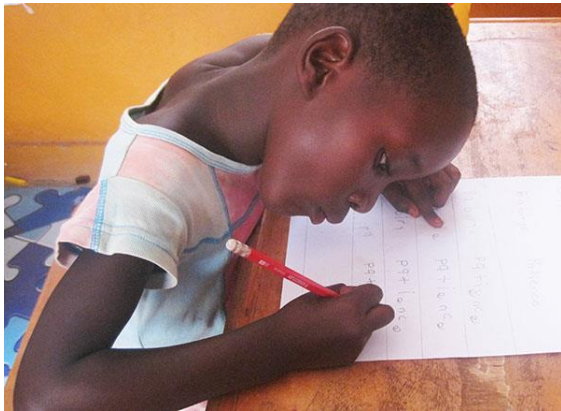
✚ In November 2008, an Australian lady Carol Menzies came to KHC to volunteer for two months. Carol a marketing consultant, helped a great deal in improving finance and administration systems, Beads for Education policies and provided assistance to staff. Carol also developed and launched the KHC website. She has also developed and facilitated training workshops for the staff and volunteers. In 2009 her husband Tom Pinkey, a teacher at Homebush High School in Australia, joined her. Tom worked with the orphans and vulnerable children's section he also organised fund raising at his school to sponsor 15 children's education for three years. Carol and Tom volunteer at KHC for 6 weeks at least once every two years and currently they with their family and friends, sponsor 29 children's education. They are such great people and it is always a pleasure to have them at KHC.





***Tom and Carol being recognised for their contribution to KHC***

- ✚ Prof. John Walley a clinical professor of International Public Health at the Leeds Institute of Health Sciences, at Leeds University (UK), also visited KHC in November 2008 and provided a lot of technical advice for our TB/HIV program. He has since donated funds for our work and also mobilized his friends and family members to support the orphans and vulnerable children.



***Education is important for these children as it prepares them for a better future.***

- ✚ Mr & Mrs Danny Witter in the (UK) were introduced to KHC by Prof. John Walley and since 2010 supported 20 orphans with school fees and have also

contributed funds for clinic repairs and equipment.

- ✚ Sinead Walsh a then PHD student at the London School of Economics visited KHC in 2010 and helped the team to develop our first strategic plan. Sinead is now the Irish Ambassador to Sierra Leone.
- ✚ Claudia Giampeietri, a freelance journalist visited KHC in 2009 and wrote stories about her experiences with KHC on her blog. She mobilised her friends and family in Italy to raise funds to buy the first home visit vehicle for KHC. She also introduced KHC to the Austrian organisation for development cooperation – HorizonT3000 and they have since supported our work with technical advisors.
- ✚ The Soroptimist group (DK) has been very supportive in providing a salary for Sarah the Medical Manager for over three years. This provided great relief to the total HR monthly requirements.
- ✚ Mayte Lomelin joined KHC in 2008 and volunteered with the orphans and vulnerable children project. She helped to set up the systems, policies and procedures and also secured funding for the purchase of equipment and costumes for the children from the Danish embassy in Kampala.
- ✚ Elin Aune volunteered at KHC for two years and greatly helped to expand the Beads for Education project. She introduced new designs and greatly improved the quality of our beads.
- ✚ Inger Darfolt volunteered at KHC from 2010 to 2011 and helped to establish the children's day care centre for HIV positive children less than 6 years old. This centre provides nutritional, emotional and medical care for the



children. Inger also linked up KHC with the Lions Club of Norway and two of the Lions members have provided sponsorship for two teenagers to join technical schools.



***Children who have benefitted from KHC Day Care program***

- ✚ Christina Dans a nurse from Sweden has to date been the longest serving volunteer at KHC. She spent three years working with the medical team, treating clients in the clinic and community. She supported many poor patients to do various investigations like x-rays, abdominal scans etc. She also often used her vehicle to visit patients in their homes.

## **PEPFAR Funding**

In 2010, KHC started to receive PEPFAR funding from the centre for diseases control (CDC) through a sub grant from the IDI-KCCA project. This funding provided a lot of support for the staff, medicines for the patients, administration requirements like rent, utility bills, computers etc. This gave the organisation a lot of stability and it presented an opportunity for investment in staff capacity building, developing policies

and putting systems in place for efficient running of the organisation.

The US government has contributed enormously to supporting the treatment of AIDS in Uganda. For this we salute and thank them for their great contribution to the fight against HIV/AIDS in Uganda.

## **The Global Partners in Care Partnership -**



In May 2011, Mr. John Mastrojohn from FHSSA, now the "Global Partners in Care" visited KHC. He came on a special mission to support palliative care development in Africa by linking up Hospices in sub-Saharan Africa with American Hospices. He later informed us that we had been partnered with Samaritan Healthcare and Hospice, New Jersey.

This partnership has been of great benefit to KHC in terms of technical assistance in managing palliative care patients and fundraising for our activities through the Beads for Education project. Special thanks to the CEO Mary Ann Boccolini, the VP-Marketing Joanne Rosen and all the members of the African partnership committee. KHC plans to work closely with Samaritan Hospice to scale up the provision of hospice and palliative care services for cancer patients in Uganda.

## **KHC 5 Year Anniversary**

Before we knew it KHC had become 5 years old on July 27<sup>th</sup> 2012. To celebrate the wonderful achievement, we organised a charity walk and a party for the staff and patients. It was a great celebration, the founder members were all smiles and so were the staff and patients who attended the event. We were pleased to have a group of volunteers from the Great Generation (UK), the Palliative Care Association of Uganda and the Ministry of Health.



A couple of weeks later we held a palliative care mini-conference at Pope John Paul Memorial Center in Kampala where over 300 participants from partner organisations attended i.e. Joint Clinical Research Center, Infectious Diseases Institute, the Center for Diseases Control, AIDS Information Center, Reach out Mbuya, the Palliative Care Association of Uganda, Mild May Uganda, the African Palliative Care Association, Hope for Children International and members of the palliative care fraternity joined us to celebrate. The conference was sponsored by HorizonT3000 and the Infectious Diseases Institute.

Special thanks to HorizonT3000 technical advisor to KHC, Ms Elisabeth Unterberger, who did a very good job in raising funds and organising the event.

The conference was also attended by the KHC Board of Directors, friends and supporters of KHC, Michael Obernoster from HorizonT3000, Dr. Amandua Jacinto the Commissioner of clinical services at the Ministry of Health, Ms. Rose Kiwanuka the Country Director of PCAU and Dr. Alex Couthino the Executive Director of the Infectious Diseases Institute. We used this opportunity to thank all the organisations and personalities that supported us from the beginning.

## **Capacity Building and Development**

Skills improvement of the management team and the staff in general was a major item on our agenda and we looked for opportunities to develop the team.

In 2008, the Friends of Reach out (FORO) supported me to complete my Masters in Public Health from the University of Limpopo in South Africa. In 2012, I got a rare opportunity to join the leadership development initiative at San Diego Hospice, California where I started a diploma in palliative care leadership which I completed in June 2014.



In 2012, Gerever completed a Master's degree in Project Planning and Management at Kampala International

University.

Sarah, the Medical Manager up graded her qualification to a bachelor's degree in nursing at the International Health Sciences University, Kampala (2013).



John Amanyire the Laboratory Manager up graded to a bachelor's degree in Laboratory Technology from Makerere University in 2010.

Alice the Community and Social Support Manager is doing a Master's degree in NGO management at Cavendish University Kampala and is scheduled to complete her course in 2015.



The Management looks for opportunities to support and train staff to enable them to improve their skills. The medical team has been well trained in comprehensive HIV care, TB/HIV co-management, palliative care etc. The finance and administration team has had a series of trainings in use of quick books, grants management, resource mobilization etc. The Skills Development and Empowerment team has received training in marketing, advertising,

mushroom growing, livestock management, and basic business skills.

In 2013, Verena Guggenberger-Senn of HorizonT3000 supported KHC to carry out an organisational development assessment. She conducted a thorough review and wrote a report suggesting changes which are being implemented on an ongoing basis.

Over the years KHC has transformed from an infant organisation to one of a well-known HIV/AIDS care and support organisations in Uganda. Most of the initial team members are still working with KHC.

We have provided comprehensive care to over 3,000 patients. All this has been made possible by the support provided by many private donors, the board of directors, the partner organisations, the development partners/funders, friends/ambassadors of KHC and our highly committed team.

## **The Pillars of KHC**

The highlight of the story of KHC is about the team that began this work and those who have joined us and carried on to help achieve our mission. The initial team who had nothing but a burning desire to be of service and help those who were the most disadvantaged in the community and were suffering and dying from AIDS.

I am very pleased that most of members of the initial team are still working with or are associated with KHC. Over the years we have recruited and trained many wonderful young people who have appreciated the Vision and the values that the founders had and they also can make their solid contribution to the growth of KHC.



To all the people who have worked and volunteered at KHC, I thank you for being one of the pillars of KHC. You have made a difference to the lives of many people and that is surely your legacy.

Thank you all for your support and may the Lord bless you.



*The KHC family*

***Our journey has only just begun  
and we plan to continue to be a  
valuable support to those who are  
the most disadvantaged in our  
community and desperately need  
our services.***

**February 2015.**