



Newsletter

Summer 2015

Registered charity in England and Wales
(1131235)

Thank you to everyone who supported Edward Mukasa in his fundraising efforts for UCTUK. He ran in the 10k relay event as part of the International Marathon and achieved third place in a fantastic 29 minutes. And he managed to raise £645 to date for the charity, which will go to support the volunteer projects at Mulago Hospital. See page 5 for details about next year's event if you are inspired to take part!

Christine Whitehouse visited Kampala in March and met with Dr Mhoira Leng, Ivan Onapito, Liz Nabirye and the rest of the volunteer team. She was able to sit in on some of the regular meetings and experience the work done by the volunteers first hand, and also meet some of the patients at the radiotherapy hostel and hear their stories.

Christine also visited the new buildings developed for the Uganda Cancer Institute which will provide significant improvements in the delivery of cancer services in the region. Our hope is that our links with the Institute will gradually extend and lead to collaborations for supporting cancer patients and their carers such as a Drop-In Centre and Information Desk.

Ivan is the co-ordinator of the volunteer project, and is currently leading the development of ideas for placing these projects on a more sustainable footing for the future with the aim being to provide properly funded permanent work placements. Christine was able to introduce Ivan to Lydia Kakooza, who was the original inspiration for the charity and who is now keen to try to develop further the support services available to cancer patients.

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A day at Mulago

I arranged to meet Ivan outside the main admin building at Mulago Hospital at 9am on a Monday morning. My hotel was only a 5 minute walk away but I had not allowed for Kampala traffic and had to take my life in my hands to cross the road to the hospital dodging between the nose-to-tail stream of matatus (VW vans) and bodaboda (motorcycle) taxis. Luckily I arrived in one piece and I needn't have worried, they have a relaxed attitude to start times!

Ivan took me first to the weekly meeting of the Palliative Care team where I was introduced to a range of clinical staff including Dr Peace, Liz Nabirye, palliative care nurses, some of the volunteers and two medical students from Aberdeen on an elective placement.

After an update on current news about the team and special events, each of the palliative care nurses gave a short presentation on patients they were involved with, identifying changes in their clinical state and care, issues such as the patient's understanding of their prognosis, how they were coping with pain, and special needs such as family issues and financial worries.

The team discussed the requirements for supporting each patient. This could involve arranging for palliative radiotherapy, provision of pain control, or some other practical assistance. Liz Nabirye also mentored the palliative care



nurses in how to interact with a patient to help them come to terms with their situation and likely outcome. Many patients are diagnosed at a late stage, so treatment

is often palliative, and helping them to understand this and come to terms with the impact on their lives and families is an important issue, and something outside the normal clinical process. As Liz explained 'they find it easier to sympathise than empathise, and this can deter them from interacting in the best way for the patient. Giving bad news is something they need encouragement to do well.'

After this meeting, I joined Liz Nabirye, Ivan and volunteers Toko and Bernard, for an information session with patients and their carers at the radiotherapy hostel. This hostel can accommodate up to 60 female patients undergoing radiotherapy treatment where it is not feasible for them travel to the hospital as a day visitor. Each patient has a carer, sometimes a husband, sister or even an older child, who can help with daily tasks, getting food, taking them to treatment, collecting medicines, or acting as translator.



Liz Nabirye led this session, giving everyone a chance to state their queries, issues and concerns. These ranged across specific medical issues, the side effects experienced, the cause of cancer, cures for cancer. Liz then talked for over an hour addressing each issue in turn and really aiming to give an understanding of the treatment pathway. Some patients did not speak either English or Lugandan, the main language in Uganda, so Toko and Bernard translated for them where possible.



After the meeting I talked to some of the patients, who had really appreciated the session and were keen to learn more. It is clear that the

work Liz is doing is very valuable and essential to helping the patients achieve the best possible outcome. As she pointed out, 'All patients referred to Mulago for cancer have to have a series of tests prior to diagnosis, which can take weeks, even before starting treatment. If this is not clearly explained, the patients think when they have their biopsy that will be the end and they will go home cured. It is important that they understand properly so that they come back at the right time for treatment.'

It was a challenging day for me, but I left the hospital feeling very inspired by the work that is being done by the team and the dedication of the staff and the volunteers, who I would like to thank for the very warm welcome I received.

Stories from the volunteers

40 Year old Byarufu Rogers lives and works in the northern part of Uganda as a teacher and is married with three children. He had to travel over 300 kilometers to come to the national referral hospital and only treatment center in Uganda to get treatment for an eye melanoma. It took him about two months on the hospital ward before he eventually started his radiotherapy treatment which was a big distress for him.



Agatha, Ronald and Toko (Volunteers) with Rogers

“It was my first time to come to Mulago Hospital and my biggest challenge was not knowing how the system was working. I spent two month without knowing exactly what was going on until the Palliative care team came in and helped explain to me everything. They also helped me to start my radiotherapy treatment. I am happy now that I am about to complete and go home because I miss my family. It’s because of the love that I have for God that he brought me such a great team of nurses and volunteers of palliative care team who have given me strength and taken away my worries and fears. They have not abandoned me. Thank you for visiting me, getting me my medications from the pharmacy I wish this

care could even go beyond when I finish my treatment and leave this hospital.”

One of the biggest challenges faced by many of our patients is the lack of adequate family and financial support while in hospital. This is partly because many patients travel long distances to come into the hospital which makes it difficult to come along with family members. In such cases, patients have had to fend for themselves, which is very challenging in the hospital. This is the situation Vivian found herself in when she came into hospital. The 27 year old lady was admitted with cervical cancer to receive radiotherapy treatment over a period of 8 weeks. The volunteers have been acting as her main carers, providing practical support like collecting her medication, helping her access meals, and wheeling her to the radiotherapy department for treatment.

“I don’t think I would have managed to get treatment if you people didn’t help me. Thank you very much for your service. I wish every patient can also get what I have got.” Vivian



Victoria, one of the Palliative Care volunteers, preparing to feed Vivian on one of her visits

Uganda marathon 2015

An email from Andy Bownds of the Uganda Marathon organizing team:

Please find the photos attached that I have been able to find. I have not been able to find any of Edward crossing the line as of yet. But these are of the finish area with some of the Uganda Marathon team congratulating him. He really ran an amazing time.



The event as a whole was even better than we originally thought. We had 1,000 people take part, 100 of which were international runners. The Uganda Marathon is already the second largest fundraising event in the whole of Uganda raising funds for organisations throughout Uganda and across the world.

All this has meant it didn't take us long to agree that we are definitely are putting the event on next year. It will be on the 5.06.15. You can already register on the website- <http://ugandamarathon.com/>

Thanks again for your support and cant wait to work with you again next year!



**Congratulations to Edward!
Who is next????**

A date for the diary...

The Uganda marathon 24th May 2015 was a great success, and many thanks to all who contributed to this.

But how about taking part next year? You or someone you know could be there, running through beautiful rural Uganda, hosted by a local family with the opportunity to meet the community, visit the projects and join in with helping KidsRunWild, as well as experiencing a very beautiful country. We ask that you pay your own air fares and raise a minimum of £1500 sponsorship for Uganda Cancer Trust UK. The money raised will be split between the Marathon's own projects (10%) and our projects at MPCU in Kampala.

If you are interested, let us know and put a note in your diary for

15th JUNE 2016 !

Here are the websites for more information:

www.ugandamarathon.com

and you can contact us on

e: info@ugandacancer.org.uk



We need your help!

If you would like to fundraise for Uganda Cancer Trust UK, here are some things you might do:

- Run the Uganda marathon!
- A budding chef – why not organise a cake bake at work.
- Do a sponsored walk.
- Auction services of people and businesses - anything from singing lessons to dinner for two
- Have a race night
- Organise a dance and show off your dance moves.
- How about a pub quiz?
- Adrenalin junkie – how about abseiling or a parachute jump?
- A keen swimmer how about a swimathon

You can go to our JustGiving or Giveway page to set up your very own fundraising page



We are also looking for corporate sponsors to ensure we have a steady stream of income for the future so if you think your company or someone you know would be able to help let us know!

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