



# Uganda Cancer Trust UK

**Our new Strategic Plan**

**2020 to 2023**

## 1. Introduction: Our journey to date

Like many things in life we did not think about the problem of cancer in Uganda until it affected someone we cared about. In the case of Uganda Cancer Trust UK, we started the charity because of the experience of our friend Lydia, who was diagnosed with breast cancer in 2009. Initially we sought to raise money for her treatment, but it soon became apparent that Lydia's experiences were not unique and that the treatment and care of people with cancer in Uganda was very different to the UK, where cancer treatment is free and there are many organisations which have been set up to support those with cancer. Lydia was lucky she was able to get support and funding for her treatment. Many in Uganda are not so lucky.

While we recognised that cancer is a huge issue in Uganda, as a small charity we wanted to focus our efforts and money where we could make the biggest difference. We are very aware that good intentions do not always lead to effective and sustainable aid. This is why the first thing we did was to get an expert (Professor Annie Young) to go to Uganda to look at cancer care there and help us work out the most effective way we could make a difference. Her input drove the development of our first strategic plan.

Today as we review what has changed and what the needs still are, we can see promising changes in Uganda. Treatment and outcomes are improving but there is still a clear gap in the information provided to patients and many people feel disempowered and unclear on what is happening to them, the treatment they need and where they can go for support. This still echoes Lydia's experience. Therefore we have decided to retain our focus on helping support the patient through their treatment. Our mission remains the same while our goals are re-focussed to suit the current situation in Uganda.

Being based in the UK, we are aware that any support we give must be locally owned and delivered in order to make it relevant and sustainable. To ensure this, we have developed strong partnerships with both local organisations, Makerere and Mulago Palliative Care Unit (MMPCU), and Uganda Cancer Society (UCS) as well as with UK charities working in a similar way in Uganda e.g. Advantage Africa.

Through targeting what we are trying to do, researching thoroughly the best way to spend our money, and partnering with accountable and effective local organisations we have made a big difference with a relatively small amount of money. We are so proud of what we've achieved to date.

But there is still much more we could and would like to be doing. We know what we can do well but we want to do more, building on what we've done to date, but reflecting the developing landscape within Uganda. This strategic review aligns our goals with the understood needs, and sets out our plan for how we achieve them.

When we look to the future we feel ambitious. We have to because there is so much more that we need to achieve. But we are also very clear about what we don't want to lose – we need to combine the best of being small, volunteer-led and value-driven with an ability to bring in more resources and deliver larger scale change.

We've achieved so much in such a small space of time and with limited resources; time is right to build on this and creating a lasting legacy.



**Christine Whitehouse,  
Chair and Founder**



**Cathryn Hannah, Founder**



**Jenny Aranha, Founder**



**Liz Minton,  
Cancer Support Specialist**



**Dr Michael Minton  
Palliative Care Physician**

## 2. Our vision, purpose and belief

### Our vision

To focus on the **journey of a cancer patient** identifying where Uganda Cancer Trust UK can best add value, enabling the community as a whole to improve the patient experience and **empowering the patient** (through the provision of information and support) to make decisions about their treatment.

### Our purpose

Uganda Cancer Trust UK is a UK based charity raising money to support cancer treatment, education and care in Uganda. We are a small charity with big ambitions. By working with local partners in Uganda and others already engaged in these issues we can make a difference.

- We support Ugandan organisations trying to improve support for cancer patients, their carers and families.
- We support individuals suffering from cancer in Uganda, where the treatment needed far exceeds their ability to pay.
- We raise awareness in the UK of the growing problem of cancer in Uganda

### Our values

We are committed to living and working by the values we have set ourselves.

- **Working in an inclusive way with real partnerships with organisations in Uganda:** We do not implement projects on the ground believing that local people and organisations are far better placed to do this. This increases the chances that our projects can be sustained.
- **Building and sustaining knowledge and skills:** We want to ensure the best quality information is easily available for people living with cancers in Uganda and those supporting them.
- **Getting the basics right first:** being realistic about what we can achieve and supportive of local context (culture, infrastructure, and environment) our projects have to be realistic and incremental.
- **Not losing sight of the individual:** We focus on the whole person living with cancer and therefore link with other services that may be available to help them and their families including getting access to food, transport, palliative care, and school fees.
- **Inclusiveness:** We are an apolitical organisation which works to ensure that the services provided are open to everyone without discrimination.

### 3. Understanding cancer in Uganda

#### *The scale of the problem*

- Uganda is a similar geographic size to the UK but with just over half the UK population. It is estimated that 21% of the population live in absolute poverty
- WHO estimates that the global cancer burden will increase by 11 million people between 2018 and 2040 and that about 10% of this increase will be in in sub-Saharan Africa (Parkin DM, Bray F et al, 2005)
- The true instances of cancer in Uganda are not known as many patients are never diagnosed. However, new cases of cancer reported in 2018 (source Globocan) were 32,617, with 21,829 deaths
- Most patients only seek treatment at a late stage, meaning that palliative care is all too often the only option and is therefore the most highly used cancer service
- Facilities for cancer treatment are limited and almost exclusively based in the capital Kampala, where there is one radiation unit (now equipped with a more modern machine), one chemotherapy unit and a shortage of cancer specialists. Uganda Cancer Institute has only 54% of its target cancer specialist posts filled. It is also estimated that only 5-10% of population have access to facilities
- Survival rates are low
- There is no NHS in Uganda and individuals need to fund their own treatment, However, with the minimum cost of breast cancer treatment double the per capita income too often people are unable to do so
- While recognition of the need to improve cancer services in Uganda is increasing, still the majority of donor and public support is focused on other diseases such as malaria, TB and HIV
- Covid restrictions have severely impacted cancer patients ability to reach their treatment centre, meet treatment costs, while support services such as hostels have additional costs of PPE to protect their workers and resident patients with no additional funding support

## 4. Understanding the new opportunities

### 4.1 What we have achieved

- Raised and invested over £60,000
  - 90% for specific cancer patient support projects
  - 5% for individual patient treatment costs
  - 5% on essential admin such as membership of UCS, donation sites etc
- In September 2010, Professor Annie Young, of the University of Warwick, undertook a scoping study on behalf of Uganda Cancer Trust UK. She met with patients, carers and medical staff at Mulago Hospital and the Uganda Cancer Institute to understand the current challenges in cancer care and support and identify where UCT UK could best use its limited resources to complement existing activities.
- Six month volunteer placement in country to build understanding, networks, and partnerships with key local organisations
- Nearly 5000 cancer patients supported
  - with direct costs or
  - by the volunteers or
  - by the Information Nurse at MMPCU
- Ongoing support for a volunteer visitors programme, including the training of volunteers run by MMPCU to help patients access information and holistic palliative care, and to provide practical and emotional support for patients and carers
- Continuing funding for the role of an information nurse to improve provision of information on cancer to patients and carers
- Strong ongoing partnerships developed with
  - Makerere and Mulago Palliative Care Unit (MMPCU, formerly MPCA, our original partner)
  - Uganda Cancer Society (UCS)
  - Advantage Africa
  - Source of the Nile Union of Persons with Albinism (SNUPA)
- And we have done all of this with no staff and a small Trustee Board.

## 4.2 Our untapped potential

- Our fundraising has been limited to date, focusing on individual giving. We now have the chance to build on this and explore grant making opportunities.
- Our supporters and followers have a strong personal commitment to the work of the charity and we can challenge ourselves to identify further opportunities for them to help us.

## Case Studies – Patient tell us about their experiences of the volunteer programme



### Juliet's story told by Vicky Kirabo, one of the volunteer team

Juliet (not real name) is a 52 yr old, diagnosed with Cancer of the cervix, sick for the last 7 years and admitted to the Uganda Cancer Institute.

She is under the care of the Palliative Care team working alongside her primary doctors, with the volunteers supporting her through her pain and symptom control. The volunteers were able to visit her and establish a good rapport with the main caregiver, Juliet's sister. Juliet had advanced disease and her kidneys were failing and thus getting weaker every day. The doctors requested a procedure that would help to revise her kidney problem, but it was too expensive and the family could not afford it due to financial constraints. This was very distressing to the daughter and sister, watching their loved one in agony and in a confused state. It seemed really a hopeless situation for them.

However, the volunteers were able to liaise with the Social Worker of the Uganda Cancer Institute to raise some funds for the procedure and this was able to bring hope and a smile to the caregivers who would always cry because of not being able to meet the financial obligations.

Through the regular visits by the volunteers, the caregivers were able to share their worries and fears, which included not being able to transport their loved one's body if she died in the hospital. This was a very painful feeling but as volunteers we informed the clinical team who then facilitated the patient discharge and also referred them to a community Palliative Care centre for continuity of care.

The family appreciated the time, help, care and love they were shown at their darkest moment and they had this to say "Thank you for loving us and visiting us. You did not know us and we did not know you but this has created a relationship between us which I would not want to end! You should extend the love to the rest of the other patients too".

She died a few days after she was discharged back home but the family was very grateful and have remained in touch.

So being a volunteer in Palliative care is both a positive and meaningful experience and it is a privilege being able to help those in need. As a volunteer, it is important to be present for the vulnerable persons and to follow them in their various physical and spiritual distresses. However, it is crucial to possess knowledge, skills and life experience, as well as a clear role, with regular support from my mentor.

As long as what I am doing is help to the patients and families, I am happy with what I do. It does not matter what it is, as long as I am of assistance, I am happy.

## Deo's Story



19 year old Deo had to drop out of school due to his illness (melanoma of the eye). He was frustrated that his illness had caused him to drop out of school. The volunteer team offered psycho social support to him and his mother as well as escorting him for his treatment at the Radiotherapy department. He said of the volunteers:

***"When I see you people coming, I get so much encouraged. When you spend time with me, I even sometimes forget that I am sick.....Please if possible you be coming to see me everyday....."***

Deo had to undergo radiotherapy treatment. The volunteers were very helpful in providing information to him and answering his questions concerning the treatment he was going to receive, its side effects as well as allaying his fears.

***"Thank you for helping me understand about my disease.....the book you gave me about radiotherapy [A Macmillan leaflet on radiotherapy] was very helpful....at least I went for treatment when I was somehow prepared to face it.....even when I began losing my hair after treatment, I had read about it in the book which was talking about losing hair"***

Deo was discharged after his treatment and was recently invited to speak at a Tumor Board Meeting for Oncologists where he shared his experiences under the care of Makerere Palliative Care Unit.

***"I want to thank the Palliative Care Team for all the care they gave me.....they helped control my pain, they answered all my questions, they helped me to get treatment and they always visited me.....I now hope to go back to school."***

## Jane's story



Jane who hails from the Northern part of Uganda (about 500 Km from Kampala) is married with 8 children. She began feeling pain in her right arm about a year ago. She visited a traditional healer who gave her some herbal medicines, however the pain continued to get worse. She went to a local Hospital where tests were done and she was diagnosed with cancer. Her arm was amputated and she was referred to Mulago Hospital for Chemo-Radiation. She is currently staying in the radiotherapy hostel as she undergoes her treatment.

***"I wish I had known earlier what my disease was, maybe I wouldn't have lost my hand. But at least I am getting my treatment and I am feeling better, I want to go back and look after my children.....when I came, I didn't know where to start from but I was helped by the volunteers who helped me find my way around since I didn't understand the language being spoken"***

## Nalubega Teddy's story



This 17 year old was diagnosed with Nasopharyngeal Carcinoma (NPC) and was admitted to Mulago Hospital.

***"I lost my parents when I was a little girl and I have been living with my sister who brought me to Mulago Hospital when I was sick. However she went back to look after her baby and left me alone. It was very difficult until the Palliative Care Team began coming to see me. They have been providing for my meals....washing for me my clothes and have paid for my investigations and always collect my drugs for me. They also come and escort me every day for my radiotherapy treatment. I thank them very much for giving me very good care because I would not manage by myself."***

Teddy was a vulnerable patient who had to fend for herself and the volunteer team was very crucial in providing her holistic care as she underwent radical radiotherapy treatment. She was discharged and will come back for review in August.

## 5. Our strategic direction: The impact we want to have

While we have achieved a lot, there is much more we can do to help those with cancer in Uganda and the charity has the following goals for our future work:

- To improve the range of support services available for cancer patients and their carers
- To enable more people with cancer to access good quality information about cancer and the care, services and treatment available;
- To support individuals to access the appropriate cancer care, services and treatment; and
- To raise awareness in the UK of cancer care in Uganda with a view to supporting the delivery of all our goals.

## **Our goal: To improve the range of support services available for cancer patients and their carers**

### **Why this is important:**

Patients in Uganda with suspected cancer face a frightening prospect. They may have financial worries, be the only breadwinner in the family, have to travel a long way to Kampala to obtain diagnosis, let alone treatment, they may only speak a local language so have difficulty communicating with clinical staff and they may not have a carer to help them. At the same time, they do not know where to go or what is going to happen to them.

The volunteer programme run by MMPCU aims to support patients practically and emotionally by listening to their problems and doing what they can to ease their path. It has been very successful and has reached out to and supported many cancer patients going through difficult times in their care journey, providing a lifeline to patients which is much appreciated. The MMPCU team includes an Information Nurse, highly knowledgeable about cancer treatment and palliative care. She has played a key role in supporting and training the volunteers in their work.

The Information Nurse has also carried out a training programme for Link Nurses within the clinical teams in the Kampala hospitals. This has helped to raise awareness of the effects of cancer treatments and the benefits palliative care can bring, and has improved communication across the board.

Longer term, provision of a patient support centre is vital not just to obtaining information about cancer and its treatment, but to co-ordinate and signpost services that can help. At the same time, it can also provide a safe space where patients and their carers can find a place to meet, rest and share their burden. UCS aims to develop a permanent support centre, a 'Patient Sanctuary', where patients and family can get information about their treatment or the help or support available to them.

### **In the next 18 months**

- We will continue to support MMPCU to recruit and train volunteers as part of the palliative care multidisciplinary team.
- We will respond to specific requests from our local partners to meet the challenges of the Covid19 pandemic to ensure that patient access to treatment is not disrupted
- We will seek funding for a 'kickstarter' project with UCS to enable the drawing up of plans and costings for a patient support centre. This will help UCS to attract funding and support for the Sanctuary within the Ugandan government and wider community

## **What we could be doing**

- Working with partners (including those providing treatment, support and advice) in Uganda and in the UK to identify innovative approaches to supporting cancer patients and helping to implement such
- In preparation for the development of a patient support centre, research potential for funding partners in the UK and globally

## **Our goal: To enable more people with cancer to access good quality information about cancer and the care, services and treatment available**

### **Why this is important:**

We believe that information empowers people and when dealing with an illness like cancer, it is critical that the patient has the information necessary to make decisions about his or her care. Too often in Uganda patients can't do this, as the doctors do not provide detailed information and there are little or no support networks for people to access. We want to change this.

Literacy rates are low, so spoken and visual tools are key to engaging with people and helping them make informed decisions about their care. The post of an information nurse has been very successful in managing and communicating essential information to cancer patients and their carers.

This period has also seen the development of the local infrastructure to support cancer services, facilitated by the American Cancer Society (ACS). UCS is providing an umbrella for many organisations, helping to co-ordinate and advocate for a more effective response to the impact of cancer within the population. An example (funded by ACS) was the completion and printing of a set of information leaflets for patients, which the Information Nurse at MMPCU was closely involved with, and these have proved very successful.

### **What we'll be doing in next 18 months:**

- We will continue to provide funding for the information and support nurse
- We will respond to requests from MMPCU to develop further information tools, and extend existing or develop new services
- We will work to try to ensure that the ongoing funding of any services is put on a sustainable footing
- We will maintain links with UCS and respond to requests for support that match with our objectives.

### **What we could be doing:**

- Developing further links with other Uganda organisations and UK charities working in Uganda to explore ways in which non-clinical services can complement cancer treatments and support patients

## **Our goal: To support individuals to access appropriate cancer care, services and treatment**

### **Why this is important:**

As mentioned previously there is no NHS in Uganda and individuals need to fund their own treatment. However, with the minimum cost of breast cancer treatment at double the per capita income, too often people are unable to do so.

### **What we'll be doing in the next 18 months:**

- We will set aside up to 10% of our funding to support individuals who cannot pay for their treatment
- We will review our current decision-making criteria to ensure decisions to support individuals are based on legitimate information and establish a new Sub Committee of our Trustee Board to verify legitimacy
- We will set up an arrangement with MMPCU to act as the gatekeeper to verify individuals' need for help with funding the cost of treatment and diagnosis. We will raise a specific fund to be used for this purpose
- Maintain a good understanding of cancer services in Uganda to ensure effective decision making
- Help people to fundraise for themselves using UCT mechanisms

### **What we could be doing**

- Strengthen our links with the Ugandan Diaspora to ensure the Ugandan Community is more actively involved in what we are doing and can help support individual cases

## **Our goal: To raise awareness in the UK of cancer care in Uganda with a view to supporting the delivery of all our goals**

### **Why this is important**

While the context in Uganda is different to that of the UK, partners in the UK can help bring much needed skills, equipment and insight to help tackle cancer in Uganda. We have worked to ensure that expertise is shared between our partners, actively making links and improving the networks of those on the ground. For example making links between MMPCU and partner organisations in the UK and Uganda.

### **What we will be doing in the next 18 months**

- Effective engagement and networking with potential donors and partners
- Creating a Friends of Uganda Cancer Trust group to widen and strengthen support to the charity
- Increasing our engagement on social media, e.g. using Facebook particularly to create communities in the UK and Uganda, more updates on Twitter and tweeting about related news and information from other organisations. Disseminating relevant information through our communication mechanisms (eg website, Twitter, Facebook)
- Working with partners with common or complementary goals in the UK and elsewhere, to identify initiatives and approaches to information provision and awareness raising that might be applicable to Uganda
- Engaging with relevant Parliamentary groups within the UK to raise awareness of the issue
- Seeking partnerships with UK medical professionals and potentially fund exchange programmes for managers and health professionals to progress policy and practice in cancer care in Uganda
- Seeking networks of professional skilled people who could share their expertise with partners in Uganda (eg helping to design leaflets, train volunteers, provide input to patient support centre development)

**What we could be doing:**

- Extending our partnerships with expertise in the UK – such as VSO and Maggie's Centres – could be the most effective way of transferring knowledge and skills
- Promoting awareness of cancer care in Uganda to UK organisations that can help with appropriate equipment and support

## 6. Delivering this plan

In order to deliver this plan we need to have clear governance and decision making processes, effective and targeted fundraising arrangements and the ability to effectively evaluate our performance on an ongoing basis.

### 6.1 Governance

We are in the process of expanding our Trustee Board to ensure we have the skills we need to deliver our ambitions and to hold ourselves to account. Priority areas will include fundraising, a clinical background and links with Uganda. We have already recruited Liz and Mike Minton who have strong clinical skills and are looking to recruit a further board member with fundraising expertise.

We are taking a staged approach to growth - evolution not revolution - to ensure that we can make decisions in a consistent, open and transparent way. There is no shortage of projects that we could fund, and the reasons why we don't fund are just as important as the reasons why we do. Resources will always be limited and we need to be able to demonstrate accountability to our funders, our supporters and our beneficiaries. As such any decision to fund a project must be

- made by the majority of the trustees;
- link to one of our published goals, and
- be a proposal that is locally owned.

We will give priority to projects that demonstrate how they will be sustainable in the longer term and we will also seek to work with any project to develop sustainable funding.

### 6.2 Fundraising

As an organisation we will need a combination of funds for our ongoing and defined work and targeted funding for specific projects and activities. In order to fund both, we will need to diversify our funding bases and produce a detailed fundraising strategy which utilises the following fundraising strands:

- Sponsored activities or events, such as bike rides, marathons, walks, cake bakes etc
- Targeting corporate organisations, including workforces that have Ugandan communities or have presence in Uganda
- Applying to charitable trusts, who have a link to Uganda or a focus on cancer

- 'Friend of Uganda Trust' - target for 2020 of having 40 and then doubling this each year thereafter. We will provide regular updates to the 'Friend of Uganda' through newsletters, the website and Facebook
- A launch event, linked to the publication of this strategy
- Selling merchandise such as Christmas cards, Ugandan crafts etc
- Crowd sourcing to fund specific projects

### **6.3 Evaluation and quality assurance**

Evidence based practice underpins every project we fund and we have required our current partner MMPCU to develop and carry out a research project to explore the information needs and impact of providing information support and to ensure effective and appropriate data collection and storage to record volunteer activity. We receive regular reports from MMPCU and would require any future partners to undertake a similar level of due diligence.