

Creating Equal Opportunities for Children with Disabilities in Western Uganda



Introduction

Kyaninga Child Development Centre is a Ugandan registered non-profit organisation, located in Fort Portal, in the Kabarole District of Western Uganda. It was founded in 2014 to create equal opportunities for children with disabilities.

Uganda has some of the most beautiful landscapes and welcoming people you'll ever encounter. Unfortunately, it is also one of the poorest countries in the world. This poverty often causes the most suffering among marginalised groups, such as children living with disabilities.

Disability affects more than 13% (2.5 million) of children in Uganda. Access to rehabilitation services is limited and invariably associated with high transport costs, long travel times, few trained therapists and limited knowledge of disability among healthcare workers. In addition, widespread local beliefs surrounding disability cause children and their families to be excluded from their communities and educational institutions. These factors combine to form huge barriers to the progress, learning and independence of many children.

Kyaninga Child Development Centre (KCDC) works to overcome these barriers and create equal opportunities for children with disabilities through a multi-pronged approach.

We provide access to a wide range of specialist, multidisciplinary therapy services, as well as specialised equipment, that allow children who were previously unable to do simple tasks such as sitting, walking or communicating to gain greater independence and lead more fulfilling lives.

In addition to providing daily comprehensive outpatient therapy at our centres, KCDC conducts a daily community outreach programme, visiting individual homes, schools, local health centres and communities in five districts, meeting the needs of clients who are unable to travel due to limited mobility or financial constraints.

Through our special education programme, we train teachers and work with local schools to ensure that children with disabilities are not excluded from the education system. We also run training programmes for community workers and health workers to raise awareness of disability and assist with early identification, which can make a significant difference to long-term developmental outcomes.

Perhaps most importantly, we work with families and their communities to raise levels of disability awareness and understanding, enhance general health and nutrition, improve livelihoods, and create peer groups that foster inclusion and support.

This holistic approach creates solutions at multiple levels — medical, therapeutic, educational, and social — to ensure that children with disabilities are no longer ignored.



How it all began

Kyaninga Child Development Centre was founded by Steve and Asha Williams, the owners of Kyaninga Lodge, and Fiona Beckerlegge, a specialist pediatric physiotherapist, as an initiative to provide much needed high quality, specialised and affordable assessment, treatment, education and support to children with disabilities, and their families and carers, to enable them to lead more fulfilling and independent lives.

When looking around for help for their own son Sidney, who was born with severe epilepsy that resulted in developmental delays, Steve and Asha realised that there were very few resources or specialists available in the area to help children with disabilities and their parents, and virtually no options at all for families with limited means.

Casting their net a little wider, Steve and Asha contacted a number of child development centres in the UK, hoping one of them might be able to put them in touch with a specialist therapist willing to come out to Uganda to help not only with Sidney, but also to establish a facility where other families in the area might likewise access affordable expert care.

It was in this way that Fiona Beckerlegge heard about the project. She is a fully qualified Specialist Pediatric Physiotherapist and member of the Chartered Society for Physiotherapy who, having previously worked in Tanzania, was happy to come to Uganda to help Sidney.

With Fiona on board, they set about registering KCDC as an NGO, looking for suitable premises, getting hold of equipment, and linking with schools, orphanages and health centres throughout the district. A personal input of \$5000 each helped get the ball rolling, and KCDC opened its doors in 2014.

Since then, KCDC has grown rapidly and is now firmly established as the go-to organisation in the area. With a team of 16 therapists and 15 support staff, plus invaluable help from international volunteers, KCDC has treated over 2,400 children over the last 4 years, with new referrals coming in every day.

In January 2018 KCDC opened a second centre in neighbouring Kasese District, and between its 2 centres now provides approximately 750 therapy sessions each month, daily community outreach visits to 28 health centres across 5 districts, as well as assisting 64 local schools with special needs teaching.



Sidney Williams - his epilepsy and developmental delay led to the founding of KCDC

KCDC is the only centre in Western Uganda providing these specialist therapy services, as well as being the only centre providing this holistic approach of community-based rehabilitation at a cost affordable to all. Because most of the families KCDC supports live in extreme poverty and do not have enough income to support the high costs of caring for a child with a disability, KCDC only charges a nominal \$1 monthly subscription fee or payment in kind of local produce, for its services.

Where we're heading

Kyaninga Child Development Centre has come a long way since it opened its doors in 2014, but with an estimated 2.5 million children in Uganda living with some form of disability, there is still a very long way to go. KCDC has big plans to expand its geographical coverage, offer a wider range of therapies and supply more mobility equipment to make a difference to the lives of more children and their families.

Expansion of community-based rehabilitation

An ambitious 3-year investment programme aims to give KCDC the capacity to support 3,000 additional children with disabilities and their families across the western region of Uganda. The major components of this plan are the opening of 2 satellite multi-disciplinary clinics in neighbouring districts within the western region, to increase accessibility and provide the urgently needed, community-based programmes. Currently, KCDC provides monthly outreach clinics to these identified districts, but due to the rapidly increasing demand as awareness grows, we are failing to provide the extensive training, awareness and ongoing support that the families require.

Two further centres will be opened in Kampala, the capital city, and in Bundibugyo District, where the same community-based model will be used, again providing for families unable to afford the private, clinic-based therapy that is currently available.

More details and funding requirements are available as a separate document.

Kyaninga Therapy and Rehabilitation Centre

The KCDC Therapy and Rehabilitation Centre is intended to provide new headquarters to accommodate the organization's expansion while creating purpose-built facilities that will include multiple diverse therapy rooms, a rehabilitation facility, a hostel for patients requiring ongoing intensive therapy and their carers, and a conference centre for our community awareness, economic empowerment and technical training sessions.

The site for the proposed construction has been secured and KCDC has entered into an agreement with the Design & Build Summer School programme at the Technical University of Munich, which sees architectural students design and oversee construction of buildings for non-profits in Africa ona pro-bono basis, under supervision of senior architects on the university faculty.

More details and funding requirements are available as a separate document.

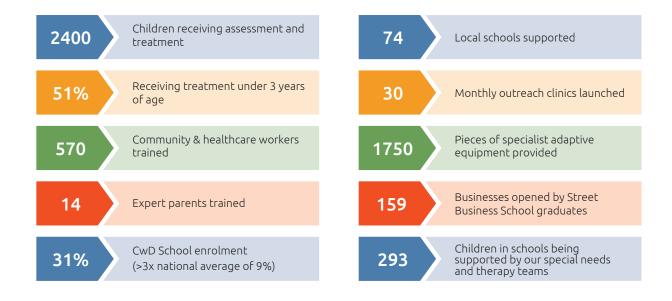
Kyaninga Innovative Design Studio (KIDS)

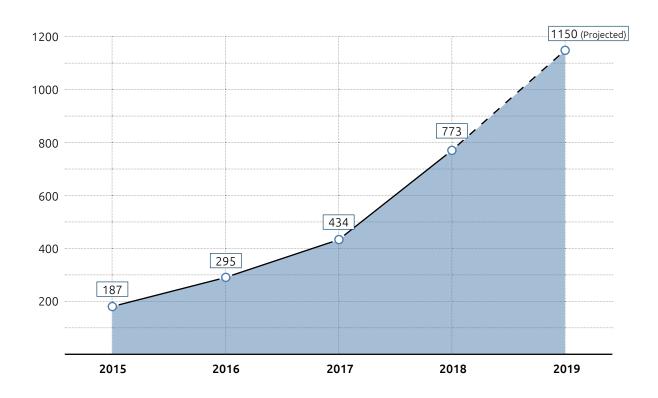
KCDC currently has a growing waiting list of 300 children with disabilities in need of wheelchairs or other mobility equipment. Currently, we are able to purchase about 10 wheelchairs a year for distribution, and receive donations of a further 5-8 annually from donors and well-wishers. These need to be adapted to the local conditions and terrain, as well as requiring fitting to each individual child.

The Kyaninga Innovation Design Studio is a proposed workshop that will design, test, develop and manufacture wheelchairs and other mobility equipment that is specifically tailored to the rural setting we operate in, allowing us to supply mobility equipment in far greater numbers, reduce waiting times and transform lives. Additional sales of equipment to third parties will help KIDS become self-sustaining by year 3, and profits thereafter will be directed towards supporting the work of KCDC.

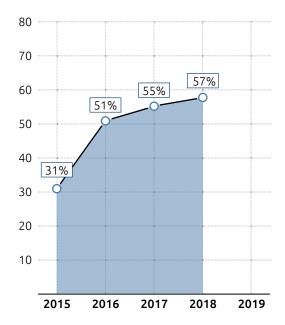
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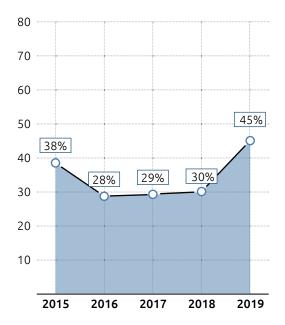
What we've achieved so far





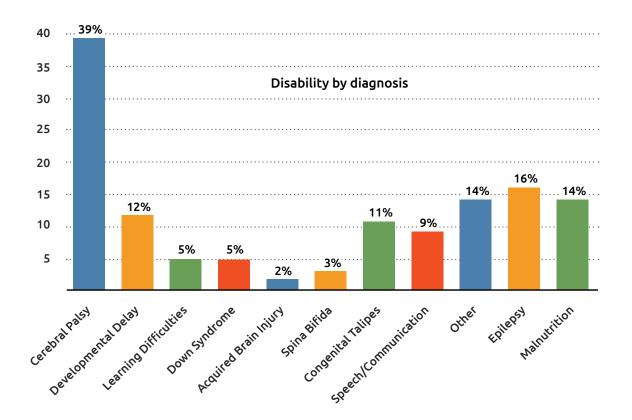
Number of new referrals per year





Percentage of referrals under 3 years of age

Percentage of school aged children with disabilities enrolled in school



Raising awareness to transform lives

Lack of knowledge and poor awareness of disability issues among families, communities and healthcare workers in Uganda has created a situation where disability often means a relinquishment of rights and an acceptance of reduced access to services such as education, health care and leisure activities. KCDC works to create equal opportunities for children with disabilities through a range of community training programmes.

Parent education and peer support programme

One of the most heartbreaking impacts we see is the sense of isolation and shame felt by parents and families of children with disabilities, who are often shunned by neighbours and relatives due to widespread beliefs that disability is contagious or an untreatable curse. Transforming parents' culturally imposed shame into a feeling of pride and empowerment is one of our main focal points, one that we concentrate on at our regular parent education and peer support groups.

Many of the parents that come to see us have become timid and withdrawn as a result of the exclusion they feel from their community caused by a lack of understanding about their child's disability. We bring parents from the same community together to discuss the issues they are facing individually, and to come up with solutions as a group. Not only does this allow for experiences to be shared and discussed in a non-judgemental, non-prejudiced environment, it also strengthens the intra-community network by encouraging parents to come together in support of one another.

Atthemeetings, we conduct short seminars addressing different aspects of disability, from understanding the different forms of disability such as epilepsy or cerebral palsy, to offering advice on everyday tasks such as positioning, feeding, communication or integrated play. Facilitated by expert parents who are themselves parents of children with disabilities, these 10-module programmes promote inclusion and participation of CWDs within the family and community, and provide understanding of the child and family experience, particularly addressing stigma.

Through information sharing, rights training and peer support, the meetings promote empowerment of caregivers and work to create 'community champions', who in turn inform and advocate for children living with disabilities within their communities, and their families, about the provisions they should be demanding from their local councillors and schools.

The encouragement, assistance and feeling of inclusion that both the parents and their children gain from these meetings has a hugely positive impact, truly transforming their outlook on life and how they are viewed by their peers, creating a 22-25% improvement in reported quality of life for caregivers, and boosting their children's health and developmental potential.



Early intervention programme

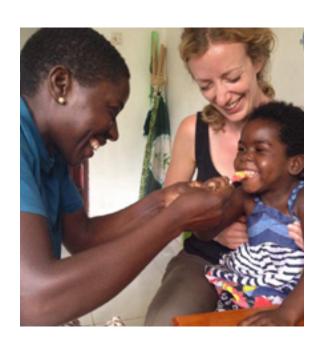
Acting early ensures that both parents and their children are given the best start and have access to all the information and support they need to ensure a bright and positive future. That's why KCDC provides early intervention training to community and healthcare workers across the five districts we work in, and as a result 50% of all children now referred to KCDC are under the age of 3 years. Learning about the normal child development stages, and being able to identify disabilities or high risk of disability in infants and young children, helps community and health workers provide timely health education to parents and caregivers, which can greatly improve the wellbeing and long-term developmental outcomes, and reduce the risk of secondary disabilities, neglect and malnutrition.



Nutrition programme

15% of all children with disabilities registered with KCDC are severely malnourished, resulting in poor weight gain, delayed growth and development, lethargy, muscle weakness and a higher risk of other illnesses. If left untreated, malnutrition may lead to severe illness and, in some cases, death. For about two thirds of the malnourished children we treat, malnutrition is due to a physical feeding difficulty such as a delayed swallow, or choking due to poor positioning or spasticity. These are difficulties that can be corrected with proper training and parental education.

KCDC's nutrition programme sets out to improve the nutritional status of all the children with disabilities we work with. This is done through individual assessment and treatment to identify feeding difficulties and demonstrate specific techniques to manage them, and by educating parents on how to best use the food supply available at home to provide a nutritious diet for their children.



Epilepsy programme

Epilepsy is a chronic condition affecting around 1% of the population worldwide, although it is twice as common in sub-Saharan Africa. It is classified as a seizure condition in which, over time, there are multiple events of abnormal electrical activity in the brain with no acute cause.

Epilepsy affects the whole family. Parents of children with epilepsy are often isolated and feel stigmatised by their child's illness, and in many cases it is difficult for them to discuss this with their families and communities.

Changing entrenched attitudes that have been passed on from one generation to another is a huge challenge, so clear health education that empowers parents through knowledge is an essential component of the community clinic.

KCDC runs epilepsy clinics at Health Centres in the surrounding districts, with a trained doctor on hand to make assessments and prescribe appropriate medication, and a community health worker to provide health education.

Multi-disciplinary specialist care

Disability can present itself in many forms, such as a physical impairment, an impairment hindering communication or one affecting mental cognition. To make sure that every aspect of a disability can be addressed, it is necessary to have multiple angles from which to approach it. KCDC employs a wide range of therapeutic services that are made available to the children and communities we work with.



Physiotherapy

Physiotherapy is an essential part of treating many disabilities. Movement and function can often be impaired by physical limitations that may be the result of birth injuries and complications, accidents or illness. Improving a child's ability to complete the smallest or simplest of tasks, such as sitting upright or holding a cup, can significantly change the level of interaction that is attainable within the family unit.

Hydrotherapy

Sometimes the children we see have such severe disabilities, or have been without appropriate care for so long, that the slightest movement can be painful or even physically impossible under the constraints of gravity. The use of a heated hydrotherapy pool can greatly reduce these discomforts by minimising the effects of gravity, allowing children to float in a warm and joint-friendly environment and achieve greater freedom and movement. At KCDC we are lucky enough to have our own hydrotherapy pool which we integrate into as many of our therapies as possible.

Occupational Therapy

For children to feel they are fully integrated in both their family and their communities, obtaining a level of functional independence in as many areas as possible can really drive progress forward. This is why occupational therapy is one of our principal therapeutic treatment methods. Here families and children alike are given skills that encourage them to develop independent means of completing daily tasks, giving both the parent and the child a greater sense of freedom.

Speech and Language Therapy

Not being able to communicate with one's family or friends can leave a child feeling isolated, trapped in a world where they are not able to convey their thoughts, feelings or desires. An inability to communicate can often be significantly improved with the right therapeutic treatment approach, and we accomplish this through our speech and language therapy department. Both verbal and non-verbal children are taught how to communicate through whatever means possible, whether it be through the use of communication cards, simple sign language or modified vocalisation.

Orthopaedic Splinting and Casting

Some of the children we see have been born with congenital deformities, such as club foot, or have soft tissue injuries that can have a severe impact on a child's mobility. Using specialist casting and splinting techniques we are able to correct and improve many of these, and help children to avoid being left with a lifelong disability that affects their mobility and potential.





Improving access to education

Equality within a society means ensuring that every individual has the same opportunities, and nowhere is this more important than in education. At KCDC we believe that all children have a right to education and that disability should not prevent a child from attending school. Safeguarding access to education for children with disabilities is, therefore, one of our key programme areas.

Nationally, only 9% of children with disabilities are enrolled into primary schools, with only 6% going on to secondary school. This is due, in part, to a lack of awareness of a child's right to access education, a limited number of teachers trained in special needs education, and inaccessible school environments.

Widespread local beliefs surrounding disability often cause disabled children and their families to be excluded from their communities, creating isolation and increased family stress, added financial burdens and a reluctance to seek help, in particular, from educational institutions. The poor understanding of disability is a huge barrier to the progress, learning and independence of most disabled children.

Through our rights training initiatives, we empower parents to advocate for greater access to education for their children, and offer to assist local schools to modify their facilities to make them accessible for children living with disabilities.

Our full-time special education teachers, supported by expert international volunteers who come out on short-term placements, provides training to teachers and teaching assistants in local schools.

The special education teachers and teaching assistants are encouraged to visit surrounding communities and help to integrate children with disabilities back into the education system, and act as advocates for a more inclusive education system within their schools and among their colleagues.

As a result of our education programme, we have now partnered with 64 local schools and helped 219 children with disabilities to enrol, children who previously were not receiving any schooling at all. Across the over 2000 children with disabilities we have treated so far, school enrolment now stands at 31%, over three and a half times the national average.



Economic empowerment for families

As we strive to create and secure our own sustainability at KCDC, we also hope to create opportunities for the communities we work in. The financial burden of caring for children with disabilities places great strain on parents and families, and offering training that helps them to create income generating ventures helps to ensure added financial security.

Entrepreneurial Education Model

One proven and successful approach we adopt is the Street Business School, a model that encourages communities to create income generating opportunities for themselves by providing training and skills in practical simplified business concepts, business plan development, capital procurement and bookkeeping.

The success of the initiative convinced us to employ two of the mothers of the children with disabilities that we work with, and train them up to be trainers for our other parents.

Not only do the Street Business School training sessions allow for business skills transfer and entrepreneurship, enabling mothers to make their own income and lift themselves out of poverty, they also provide a perfect opportunity to help mothers understand their rights as parents and advocate for them accordingly.

We hope that by incorporating this model into our inclusive education programme, we will free-up time for parents and give them the skills to use this time to create different revenue generating schemes.

Our results so far indicate that the model is already making a positive impact for our parents and their children. Since starting the Street Business School, parents who have passed through the course and graduated have gone on to open a combined 159 new businesses, with the extra revenue generated creating improved financial stability for their families.







Working towards sustainability

Since we opened in 2014 the demand for Kyaninga Child Development Centre's services has been overwhelming and continues to grow, and KCDC continues to expand in order to be able to provide care to more children over a wider area. However, as our scope expands our operating costs expand too. In order for KCDC to become sustainable and less reliant on donor funding, we have a number of fundraising and income generating activities that contribute much needed funds.

Annual fundraising sporting events

For three weekends each year, our partner organisation, Kyaninga Lodge, becomes a hive of neon lycra and sinewy limbs as it plays host to our annual sporting fundraising events, each providing the opportunity to take on a unique physical challenge amid some of the country's most spectacular scenery.

First up in the rotation is the Kyaninga Triathlon, which takes place in May. The annual Kyaninga Triathlon was the first of our fundraising ventures and has over the years grown to become a true highlight in the Ugandan sporting calendar, attracting well over a hundred athletes and even receiving international attention and a three-page spread in the UK's No. 1 triathlon magazine, Triathlon220. Then, towards the end of the year, the Running the Rift Marathon and Ride the Rift Sportive mountain bike race follow hot on each other's heels in late November and early December.

All three events attract a good number of participants from within Uganda, including Ugandan paralympian silver medallist David Emong, who we are very proud to have as our ambassador. In conjunction with our UK-based partners, they also pull-in a small but growing number of intrepid athletes from around the world, keen to combine a sporting event with an African adventure. Convincing yourself to do something as crazy as a triathlon or a marathon on the equator would take some pretty good reasons, but what could be more compelling than knowing that all the blood, sweat and tears (and mainly the entrance fees) are all for a good cause?

The event days themselves are lively affairs. The organisers, timekeepers, marshals and support staff arrive early to get everything set up and the competitions under way before the day heats up too much. Once the competitors have set off, many of the spectators, companions, spouses and children choose to take part in a 5KM fun run around Lake Kyaninga, keeping everyone involved and contributing to the carnival atmosphere of the day.













For many, the highlight of the day comes after the races are over in the shape of the post-race prize-giving ceremony and especially the hog-roast that follows it, which has now become something of a social event drawing in friends and neighbours from the Fort Portal area. For those not too tired after the day's exertions, the festivities often continue into the wee hours.

All three sporting events are run entirely on a not for profit basis and are intended to provide a challenging event for sporting enthusiasts and a fun day out for the whole family and, more importantly, to raise much needed funds for KCDC. Admission fees from all the events, supplemented by generous donations from many of the competitors who raise money in the form of sponsorships, give us a much-needed financial boost.

Sustainability through delicious cheese

Our most substantial sustainability initiative is the Kyaninga Dairy project, an income generating scheme that supports KCDC through the sale of some of the most delicious cheese you are ever likely to taste.

Having grown up on a farm in Herefordshire, it was inevitable that at some point the skills that KCDC director Steve Williams learnt as a child would be put to good use. Kyaninga Dairy was established in 2016 with the help of experts Conan and Rachel from Neal's Yard Creamery in the UK, who supply Harrods in London among others, and who very kindly came out to Fort Portal to guide and assist us to set up the facility, train staff and get production under way.

A fundraising drive at the end of 2016 raised enough money to buy a small herd of goats, and with the addition of 25 goats imported from South Africa in 2017 the number of milking goats is now nearing 100. The herd will continue to grow slowly through Kyaninga Dairy's breeding programme, and we hope to be able to boost production through the purchase of some more goats too. In the meantime Kyaninga Dairy has begun producing an equally delicious cow's milk cheese.

The cheese is sold to restaurants and hotels, and is available from several outlets in Kampala, Jinja and Mbarara. So far, response has been overwhelmingly positive and some months the Dairy struggles to produce enough cheese to meet demand. We anticipate that as the dairy becomes more established and production levels rise, revenue raised from cheese sales will represent a growing contribution to KCDC's annual budget.

Steve's childhood farm operated a community inclusion programme that offered employment opportunities for adults living with disabilities, giving them a meaningful role within the business and integrating them into the farm's working team. Having seen the benefits of this first hand, Steve was determined to replicate this model in Uganda and Kyaninga Dairy now provides employment to adults living with disabilities who help with the running of the farm and in the cheese production. As well as challenging local beliefs that disability means inability, the programme provides a much needed platform from which to advocate for more inclusive employment opportunities generally.

The final and, without doubt most enjoyable, contribution Kyaninga Dairy makes to KCDC is the

weekly farm day. Every Saturday we invite parents and their children to come up to the farm and help with the feeding of the baby goats, providing a fantastic opportunity to stroke and pet the animals. The therapeutic benefits children gain from such interactions with animals have long been known, but seeing them happen before your very eyes is always a special and moving moment and we wholeheartedly recommend coming along if you have the opportunity.









Omugisa Programme

Omugisa means opportunity in the local Rutooro language. Kyaninga Child Development Centre, in partnership with Kyaninga Dairy, runs a weekly livelihood skills programme for children and youth with a wide range of physical, intellectual and communication disabilities and their families. This 6-week programme teaches care of animals, including goats, pigs, cows and donkeys, gardening skills, local arts and crafts, personal care and hygiene, sexual and reproductive health and inclusive sports. The programme provides vocational skills that can be used at home, as well as important social and communication skills that lead to increased self-esteem and self-confidence and greater opportunities for the future.

30-40 children participate in the programme each week.

How to get involved

KCDC depends in large part on the goodwill of donors, friends and well-wishers. If you are interested in supporting us and getting involved, here's how you can help.

Volunteer at KCDC

With demand for KCDC's services growing every day, we are always looking for volunteers to come and share their knowledge and skills with us, whether just for a few weeks or a longer period.

If you are interested in joining our team and making a difference to the lives of children with disabilities in Uganda, or know of someone who might be, please visit our website or contact us directly.

Make a donation

You can get involved by letting your family, friends and colleagues know about the great work we are doing.

If you (or someone you know) are planning a fundraising event, then please consider KCDC as a beneficiary. We are a registered charity on **Just Giving** and **Virgin Money Giving** and also gratefully receive donations via **PayPal.** All the details can be found on our website or you can contact us directly. And don't forget that you can support KCDC while shopping online through www.giveasyoulive.co.uk and **Amazon Smile** – just select KCDC as your preferred charity.

Take part in on of our sporting events

You can even come and take part in one of our sporting events and raise money for the centre through sponsorships. Better still, get a team of friends or colleagues together and make it an adventure of a lifetime.





Come and visit us

Why not combine a visit to see the amazing work the Kyaninga family do with a stay at Uganda's most breathtaking lodge?

Kyaninga Lodge is just 15 minutes from Fort Portal town, where KCDC is based.

The area is a favourite destination in Uganda due to its dazzling scenery of verdant hills, sprawling tea plantations and volcanic crater lakes, as well as its proximity to four of Uganda's magnificent national parks, Kibale Forest, Rwenzori Mountains, Semuliki and Queen Elizabeth.

Perched on the rim of an ancient volcanic crater lake with spectacular views of the legendary Mountains of the Moon in the distance, Kyaninga Lodge offers nine beautifully appointed and spacious thatched cabins featuring private verandahs, massive beds decked with soft bedlinen and pillows, and exquisite Elgon Olive and marble en-suite bathrooms.

The main lodge building, raised on stilts and entirely built from hand carved eucalyptus logs, is an impressive engineering achievement. Its wooden decks and swimming pool overlook the stunning Lake Kyaninga, a deep prehistoric crater lake fringed with tropical forest that is home to abundant bird-life and diverse primate species.

Guests are welcome to visit KCDC to find out more about what we do and take part in one of our daily community outreach visits, or to explore the Kyaninga Dairy to learn about the cheese making process and take part in one of our community farm days, or to discover all about the work the Kyaninga Forestry Foundation does to preserve indigenous trees and biodiversity in the area.



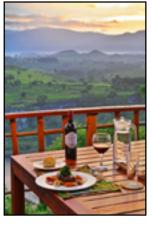














Acknowledgement

KCDC has come a long way since we first opened our doors in 2014. The progress we have made is thanks in no small part to the fantastic relationships we have formed with our many partners, donors and well-wishers. We are immensely grateful to them for the financial support, equipment donations, technical know-how and expert advice they have given us, and we look forward to continuing to work together for many years to come.

Our partners







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