



CEHURD

REBOUND | INNOVATE | SUSTAIN



THE JOURNEY OF CEHURD

10 YEARS
OF SOCIAL JUSTICE IN HEALTH

Our Vision

A society in which social justice and human rights in health systems are realised.

Our Mission

To advance health rights of vulnerable communities through litigation, advocacy and research.

Our Goal

The Overall Goal of CEHURD is
“Enjoyment and Observance of Health and Human Rights by All”



Introduction

Ten years ago, the Center for Health, Human Rights and Development (CEHURD) began with a vision of a health system that reflected social justice and human rights. Through a combination of strategic litigation, campaigns, community empowerment and knowledge building, CEHURD has brought that vision closer to reality. With the 10th anniversary of the organisation's founding, there is an opportunity to reflect on CEHURD's myriad accomplishments and to consider the ideas, the effort and — most importantly — the people who made them possible.

CEHURD began with an idea of ensuring the health rights of everyone, but especially Uganda's vulnerable communities. Ten years later, it has emerged as a leader in the field, with a reputation for using bold strategies to realize and expand the right to health and those who have access to it.

"It started at a time when issues of health and human rights in the country, especially adopting a rights-based approach to health, were nascent," said Professor Ben Twinomugisha, the Chairperson of CEHURD's Board of Directors. "Very few lawyers were engaged in questions of health."

Through its use of strategic litigation, CEHURD has sought to confirm that Ugandans do have a right to health. *"The strategic cases that have been filed over time have greatly contributed to the jurisprudence and the realisation of the right to health in Uganda," said Stanley Okecho, a lawyer who previously volunteered in CEHURD's Strategic Litigation Programme. "The right to health is not expressly stated and CEHURD's contribution is in the realisation of the right to health."*

The value of those cases extends beyond the precedent that is set, said Juliana Nantaba, who worked in CEHURD's Community Empowerment Programme from 2012 to 2015. *"There is also having a case in court and that generating publicity or amplifying different issues around health rights and then engaging duty bearers," she said. "Hearing them start to articulate those issues while they engage with the people that elect them."* Which is why CEHURD's other programs are as critical to the organisation's mission as Strategic Litigation.

CEHURD has created grassroots networks to make people aware of exactly what rights and services they are entitled to and to train them to advocate for those rights.

Those advocates also become monitors within their communities, standing up for the rights of other patients and identifying potential new cases to be litigated. In parallel with its strategic litigation, CEHURD has conducted extensive research on everything from the state of the health system to intellectual property policies. It has also run advocacy programs and developed networks of allied institutions. Combining pressure and information, CEHURD has pushed officials to use their powers to expand the right to health and access to medicines.

“CEHURD has brought that unique perspective of strategic litigation, but also building strong partnerships with medical professionals to advocate for change in the health sector for the good of everyone,” said Dr. Ekwaro Obuku, the President of the Uganda Medical Association.

The organisation’s success depends on the interlinked nature of these programs, each rooted in common values. Those include an emphasis on building connections — from the grassroots to regional and international organizations, on raising awareness and knowledge, on empowering all people — whether they are health workers or policymakers — and on doing all of this transparently, with the highest ethical standards and with accountability to the Ugandan people.

This is only possible because of the dedicated — and constantly growing — staff, which has repeatedly demonstrated its ability to lead on the efforts central to CEHURD’s mission.

In Uganda, across the region and even throughout the international community, CEHURD has opened up new frontiers for what is possible when it comes to advocating for the right to health. This is a dramatic change from 10 years ago.

“At the time CEHURD was founded, it was unheard of to advocate for this,” said Emmanuel Tumuhaise, another former volunteer in the Strategic Litigation Programme. “If the government came out and said we do not have the resources for adequate healthcare, you had to believe what the government said. CEHURD showed us that these are your rights that you’re entitled to as a human being. We can actually demand for things.”

The following pages will chart how CEHURD has revolutionised health rights advocacy in Uganda over the past 10 years, while highlighting the victories and lessons that will guide the next 10.



Strategic Litigation Programme



From its origin, CEHURD has been a trailblazer in testing the justiciability of the right to health — to the benefit of Ugandans across the country. Working with a variety of allies and activists, CEHURD has strategically filed cases that have strengthened controls around tobacco use, freed patients being held in health facilities for being unable to pay their bills and challenged regressive mental health treatment.

“Unlike conventional non-governmental organisations, CEHURD not only does advocacy on the right to health, but it also goes the extra mile to file cases that are pivotal in addressing human rights violations, in particular the right to health,” said Stanley Okecho, a lawyer who worked as a volunteer in CEHURD’s Strategic Litigation Programme.

Since its founding 10 years ago, the organisation has filed 35 cases and reached eight resolutions. But it is Constitutional Petition 16 of 2011 that has become the benchmark of CEHURD’s work. And the Supreme Court’s unanimous 2015 ruling overturning the Constitutional Court’s earlier striking out of the case is among CEHURD’s signature achievements in its first 10 years of existence.

“It is very important,” said Professor Ben Twinomugisha, the chairperson of the Board of Directors. “It has brought maternal health questions to the fore in this country.”

CEHURD originally filed the case on March 4, 2011, on behalf of the families of Jennifer Anguko and Sylvia Nalubowa, both of whom suffered preventable deaths while in labour. At the heart of the case was an assertion that Uganda was failing to provide basic maternal health commodities, contributing to a staggering rate of 16 pregnant women dying each day from preventable complications.

While Uganda’s 1995 Constitution does not expressly guarantee the right to health in the bill of rights, CEHURD has argued that failing to prevent these deaths violated constitutional guarantees that include the right to access health services and a demand that Government takes all practical measures to provide basic medical services. The Constitution also guarantees the right to life, to equality and non-discrimination and freedom from torture, cruel, inhuman and degrading treatment. In failing to prevent Anguko’s and Nalubowa’s deaths, CEHURD alleged, Uganda had violated these guarantees.

The Constitutional Court attempted to dismiss the case in 2012, agreeing with the attorney general’s argument that only the executive had the authority to set health priorities. The Supreme Court unanimously rejected that decision three years later and instructed the Constitutional Court to determine whether the Ugandan government had taken all measures to provide maternal health services.

Even as CEHURD waits for the Constitutional Court to deliver its decision, Constitutional Petition 16 has already had a profound impact. It has become a model case for litigating the right to health and guided new efforts by CEHURD. *“The strategic cases that have been filed over time have greatly contributed to the jurisprudence and the realisation of the right to health in Uganda,” Okecho said.*

The significance of CEHURD’s advances in defining a right to health became clear in the 2015 ruling in the case CEHURD vs. Nakeseke District Local Government HCCS 111 . CEHURD filed the case in 2012 following the death of Irene Nanteza, a pregnant woman, who died at Nakeseke District Hospital after suffering an obstructed labour. Despite being alerted to Nanteza’s condition, the doctor on duty left her to suffer for more than eight hours before arriving to provide assistance. He was too late. Following the model it had established with the 2011 case, CEHURD sought to hold the Local Government accountable for violating Nanteza’s right to health. The High Court found that women in Uganda have a right to emergency obstetric care and the

district vicariously liable for the doctor's failures. Nanteza's husband was awarded 35 million Ugandan shillings in compensation.

"Initially no one really took the right to health as important," Okecho said. "But when CEHURD got on board, these cases have had an impact on the government. Policies have been influenced. And the conversation on the right to health has finally caught up with Uganda."

CEHURD's unprecedented success in utilising litigation to define and uphold a right to health has been emulated across sectors, across the region and around the world. *"More and more now, you'll see advocates going to court on many issues. On other, broader issues, like education," said Denis Kibira, the executive director of HEPS-Uganda. "When someone says they're taking you to court, you'll act. It has awakened the policy space in Uganda."*

And as a strategy, it has expanded beyond the courtroom. CEHURD is also engaging quasi-judicial bodies, tribunals and private law firms to demand justice in health. In a case determined by the Uganda Medical and Dental Practitioner's Council in 2018, CEHURD alleged that a postgraduate surgery student neglected a pregnant woman in his care. She ultimately died during delivery. The Council suspended the doctor's license for a year, setting a precedent on professional punishment for medical negligence in this country.

Ultimately, experts said, it is possible to draw a direct line between CEHURD's efforts and a reduction in maternal mortality and overall improvement in health rights in Uganda. *"It caused Ugandans to start looking at maternal deaths as an issue in Uganda," said Geoffrey Opio Atim, the health and rights program officer at the Open Society Initiative for Eastern Africa, which contributes funding to CEHURD. "It created a lot of advocacy around maternal deaths in Uganda."*

Uganda's maternal mortality rate has dropped from 432 maternal deaths for every 100,000 live births in 2011 to 336 deaths per 100,000 live births in 2016, according to the Uganda Demographic and Health Surveys. *"You cannot underestimate the contribution of [CEHURD's] work in this," Kibira said.*





Campaigns, Partnerships and Networking Program



Central to CEHURD's mission of advancing health rights for vulnerable communities is shifting social norms, practices, policies and customs that prevent people's realisation of those rights. The question CEHURD's Campaign, Partnerships and Networking Programme confronts is how best to do that.

The programme builds on the analysis of how laws, policies, norms and practices undermine health rights and how they can be changed. This knowledge then guides strategies for engaging on an issue and achieving a remedy. That engagement might take the form of building alliances between policymakers and subject experts or it might lead to a demonstration through the streets of Kampala. It has often been both.

CEHURD's work around sexual reproductive health and rights (SRHR) has been particularly significant and it has been at the centre of the organisation's work since CEHURD first challenged the state's failure to address preventable maternal deaths.

The campaign has been bolstered by emerging data that prove a combination of policies and norms are preventing women from making decisions about their

own bodies in Uganda. SRHR is a controversial topic, with religious and cultural perspectives shaping policy debates and, ultimately, what services Ugandans have access to. Unfortunately, this has taken the form of limited exposure to sexuality education and reduced access to family planning services, leading to increasing numbers of unwanted pregnancies. Because abortion remains illegal in Uganda except in instances where it would save the life of the expectant mother, some women pursue unsafe methods to end unwanted pregnancies. This puts those women at extraordinary risk — both because of the immediate danger to their health and safety, but also because they might be denied post-abortion treatment, which can also lead to their death or serious injury.

CEHURD mounted a campaign to address the crisis created by a regressive SRHR environment with the goals of improving people's wellbeing, promoting access to information and promoting gender equality. That campaign began by collecting information on the extent of the problem and drawing guidance from other organisations and experts already engaged on the issue.

It also included building a network of like-minded organisations and activists. Building partnerships has always been at the core of CEHURD's work — part of an understanding that civic space is narrowing and there is a need to help strengthen like-minded organisations. In the particular case of the SRHR campaign, CEHURD has served as the secretariat for two coalitions since 2012 — the Coalition to Stop Maternal Mortality Due to Unsafe Abortion (CSMMUA) and the Coalition to Stop Maternal Mortality in Uganda (CSMMU). These coalitions serve as vessels for setting priorities, organising and beginning to build momentum around these issues. There are over 30 organisations and individual members belonging to CSMMUA while CSMMU boasts of over 500 national and international members nationally — both individuals and organisations.

With the support of these allied organisations and individuals, CEHURD has then taken on the work of raising awareness and sensitising communities on the dangers posed by the current environment around SRHR. And then harnessing that awareness to press for changes in policies and perceptions. These activities range from demonstrations to dialogues and advocacy meetings with policymaker through which the team generates interest, and potential champions, linking activists and decisionmakers to vital resources that help them make informed policies and become more effective advocates, themselves.

Dennis Jjuuko, a former CEHURD employee, said this was especially true of Parliament, where CEHURD identified champions and then *“we would take them to residential workshops to bring them up to speed with the legal and policy frameworks on the right to health. We were ensuring they understand things better and are able to debate on the floor of Parliament. Whenever they want to debate, we furnish them with enough literature. We thought that that approach could help in shifting the narrative in that space.”*

These efforts are changing the conversation around SRHR in Uganda and helping facilitate better services for Ugandan women. *“The key thing that CEHURD has done in reproductive health is sensitising the stakeholders on the options,”* said Dr. Ekwaro Obuku, the president of the Uganda Medical Association. *“The stakeholders are now more informed, though the decision to be made is a political one.”*

This progress was underscored in July 2019 when CEHURD was able to convene a Conversation on Sexual and Reproductive Health Rights Movement Building in Entebbe that brought together 45 activists, policymakers, funding partners and other interested participants presenting another opportunity to reorient the approach to SRHR services in Uganda.

Victories have been celebrated and setbacks have been used as opportunities to learn, to recalibrate and to redouble institutional efforts. *“We kept pushing,”* Jjuuko said. *“Religious and cultural beliefs shouldn’t permeate. Religion will not take precedence over the right to health in the making of policies.”*

And then CEHURD has paid it forward. The organisation has been at the centre of global events, including the 2018 International AIDS Conference (IAC), sharing its experiences with people eager to learn from its success. CEHURD has participated in international efforts to push back against the Global



Gag Rule the United States government's policy that prevents any American funding for organisations that provide or recommend abortion services. The organisation used the IAC platform to advocate for a repeal of the Global Gag Rule and also participated in a pre-conference event where team members shared their experience running an SRHR campaign in a restrictive environment.

One critical lesson has been that it is possible to have multiple aspects of a campaign running simultaneously. In fact, it has proved critical to leverage pressure from public demonstrations to score meetings with policymakers and push for reforms. CEHURD has also demonstrated an understanding that there are various actors who participate in policymaking, all of whom need to be engaged. Finally, CEHURD has seized on the value of consistent monitoring. In addition to a robust program of advocacy, the Campaigns, Partnerships and Networking Programme is vigilant about guarding its successes to ensure that officials deliver on the promises they have made to improve Uganda's health system.

Within CEHURD, these lessons have guided its numerous campaigns, including efforts to improve mental health services and to end the incarceration of patients who are unable to pay their bills. They have indeed complemented and improved CEHURD's other programmes and activities.





Community Empowerment Programme



At its most fundamental level, CEHURD's Community Empowerment Programme is building community knowledge about the right to health, but also equipping community members with the ability to advocate for those rights and to exercise their agency. It is also holding duty bearers responsible, while fostering connections with those officials so that they can eventually work together with communities to protect health rights.

The Community Empowerment Programme is woven into CEHURD's other programs, as community members identify situations ripe for strategic litigation and generate evidence to contribute to knowledge management efforts. And it is seeding a grassroots effort that is blossoming into a national movement, its leaders emerging from within those communities and connecting with other networks.

It is also CEHURD's face to communities and the path through which the institution comes into contact with the most Ugandans. In cultivating the demand for health and human rights through its Community Empowerment Programme, CEHURD is also developing a network of allies to shore up its future efforts to advance health rights for vulnerable communities.

CEHURD has employed several models to empower communities. In its most recent strategic phase, the organisation has turned to health clubs, community score cards and Legal Empowerment and Social Accountability (LESA), which grounds communities in knowledge about their rights to health care and helps them access justice when those rights are violated. At the heart of the Community Empowerment Programme, though, are the community health advocates (CHAs).

The CHA programme began in 2013 as a pilot program in eight sub-counties across three districts. CHAs are drawn from citizens who are invested in improving health care for their communities. Through regular trainings, they become experts on health rights, advocates for their communities and liaisons to both officials and to CEHURD. Edith Sifuna became interested when representatives from CEHURD visited her town, Buikwe, and gave a presentation in August 2015.

“After talking to us about health rights, I realised that the condition that was happening on the side of health in our community was really wanting,” she recalls. “I got the idea of coming up from my community to realise the change in health service delivery and also to support the local people to achieve the basic standard of health service from duty bearers, from community leaders and also the policymakers and health workers.”

A CHA's responsibilities are diverse. They monitor their communities to ensure people are receiving the treatment required under Uganda's Patient's Charter. When services fall short, they can step in to provide patients with critical information to help them advocate for themselves or to advocate on their behalf. Those services can be life-saving. They also identify and document health right violations and gather evidence that could be used for strategic litigation and to advance district and national advocacy efforts.

Many of these activities have the potential to put them at odds with community leaders and duty bearers, but they also work with those officials to educate them about the obligations they have to their constituents and help convert them to health rights advocates, as well.

In Buikwe, Sifuna said that health workers and district officials initially saw the CHAs as spies. *“With our engagement and the way we are working with them and the change we are seeing, they are more welcoming,” she said.* Officials now regularly call her for updates on health situations in the community.

The result is a greater awareness of and respect for health rights across the communities where the CHAs are working.

“Sometimes you would go to the community and have a conversation around how desperate they were,” said Juliana Nantaba, who worked in the Community Empowerment Programme for 2012 until 2015. “They were viewing health services as if the health worker is doing them a favour to provide services. That shifted to them being able to demand for themselves. Moving from being passive recipients to being active and informed people who demand for their services and their right to health within their community.”

It is also helping to catalyse national advocacy efforts. Critical to those efforts is building cross-movement collaboration at district levels and below and then connecting those grassroots efforts to national advocacy networks. That means CHAs have been elevated to national leaders of the movement for health and human rights.

The programme’s success is reflected in its growth. There are now CHAs present in 10 districts and similar structures that have emerged in other communities.

The CSAs are only one in a suite of tools that includes LESA, health clubs and community score cards CEHURD has developed for empowering communities with the knowledge and skills to act as their own advocates. Through the Community Empowerment Programme, CEHURD has cultivated a demand for health rights and then helped communities hold officials accountable.

The Community Empowerment Program will continue to scale up its existing models, but also deploy new approaches. That includes engaging young people who can then act as ambassadors to their peers in increasing the demands for SRHR services in their districts. There are also plans in place to strengthen Health Unit Management Committees and continue to improve local oversight of health services.



Knowledge Management Programme



CEHURD is best known as a leader in advocacy and strategic litigation, but it is also a research hub. The organisation has spent the last 10 years developing a body of knowledge around the right to health that has guided its activism and litigation, but also broader national policy and legislation. That research has also surfaced underacknowledged issues and encouraged legislators, journalists, funders and other civil society groups to confront them.

The programme has produced more than 100 publications so far, including: analysis and laws; policy briefs and digests; information, education and communication materials on jurisprudence in litigating health and human rights; and national-level research on abortion and life-saving commodities.

“This is one of the strengths of CEHURD, that their strategies and interventions are informed by lots of research,” said Dr. Ekwaro Obuku, the president of the Uganda Medical Association.

In one example, with its August 2018 scoping assessment of the Global Financing Facility (GFF) for Reproductive, Maternal, Newborn, Child and Adolescent Health as a development funding model, CEHURD was out in front on what has subsequently been recognised as a significant international issue.

Geoffrey Opio Atim, the health and rights program officer with the Open Society Institute for Eastern African (OSIEA), said that CEHURD Executive Director Moses Mulumba began raising the issue of GFF years ago in discussions the two were having. *“He was looking at issues where no one would look at it,” Atim said. “Challenging and questioning it.”*

The United Nations and World Bank introduced the GFF model in 2015 in a bid to close the annual financing gap when it came to global health issues and contribute to eliminating preventable maternal, child and adolescent deaths. The GFF draws and pools funding from the World Bank, partner donor countries and private funders. A World Bank-hosted secretariat then uses that pooled funding to attract additional money from other sources, including domestic governments and the private sector for initiatives centred on achieving the Sustainable Development Goals.

CEHURD was one of the first organisations to begin asking how national and sub-national actors were involved in designing the potential projects and to consider how ready Uganda was to actually implement GFF projects.

What CEHURD researchers found is an approach that spoke to universal values, including leaving no one behind, and also included novel initiatives, like the direct funding of health facilities. But there were broader conceptual flaws, including a paternalistic approach to funding and a failure to take into account local contexts.

CEHURD ultimately issued a list of recommendations, including creating a country team to negotiate with donors and implement the projects and reconsidering a results-based-financing approach to the disbursement of GFF funds.

The report’s publication generated an unprecedented interest in the GFF among civil society groups in the region, guiding several conference sessions and influencing research efforts. Atim said that CEHURD’s work has spurred OSIEA to take a closer look at the GFF. And the report has also strengthened CEHURD’s relationship with Uganda’s Ministry of Health around its efforts to provide health services centred on a human-rights based approach.

Where the evaluation of the GFF demonstrated CEHURD's capacity to tackle a global issue from a national perspective, the organisation also has the ability to conduct research that illuminates critical issues happening within Uganda.

A December 2016 report on human rights-based approaches to health care delivery in selected parts of northern and central Uganda is a prime example. The report arose from complaints the Uganda National Commission for UNESCO (UNATCOM) received about the declining state of Uganda's health care and, in particular, gaps in accessibility, especially for women and for the poor, disabled and other marginalized groups.

Working with UNATCOM, CEHURD conducted research, including assessments of whether selected facilities were complying with human rights-based principles in providing services, to ultimately offer recommendations on better integration of human rights-based approaches to health care.

In his recommendations to accompany the report's publication, Uganda's director general of health services called for increased support in resources for the health sector, including more qualified personnel and improved facilitation for them.

Effective advocacy tools in and of themselves, the reports, studies and documents generated by the Knowledge Management Programme are also the backbone of CEHURD's other activities. The information generated helps guide and bolster the organisation's education, advocacy and lobbying efforts, while documenting the advancements of CEHURD's strategic litigation and campaigns made in securing the right to health for Ugandans.





Institutional Growth



Building a well-grounded organisation is CEHURD's actual fifth area of focus — and perhaps its most important.

Delivering on all of these programmatic efforts requires a staff of talented, tireless advocates, experts and lawyers, that has expanded to meet CEHURD's increasing output over the past 10 years. From 6 employees and three programmes, the organisation now employs 42 people across four different strategic areas. It also maintains a network of volunteers, who bring their passion and skills to the CEHURD office.

While allied organizations and individuals have been critical to the success of CEHURD's programmes, there is another network of institutions that have also allowed CEHURD to thrive. These are the donors who have strategically shaped and financially supported CEHURD's work.

It has also been a decade of actual growth. From its origins on Tufnell Drive in Kamwokya to Sebbowa Road in Ntinda, CEHURD has built its office premises located on Plot 4008 Justice Road, Canaan Sites, Nakwero.

To continue building and maintaining an organisation that is strong, robust, strategic and nimble enough to seize on opportunities, CEHURD has developed a series of six management priorities. These will help set the institutional objectives for the coming years. They include:

- Strengthened governance systems
- Strengthened human resources and staff wellness
- Maintain robust monitoring, evaluation, learning and financial systems
- Strengthened resource mobilisation
- Quality assurance and risk management
- Explore sustainability for CEHURD



Conclusion

Ten years ago, the right of vulnerable communities in Uganda to quality health care was rarely discussed. And when the government failed to meet that obligation, that failure was rarely challenged. With its founding, CEHURD changed all of that. And its efforts ensure there will be no retreating.

Over the past 10 years, CEHURD has not only transformed advocacy around the right to health, it has laid a foundation of grassroots activists and allied organisations who have seized on this mission and expanded it across the country and the region.

“Before CEHURD, [civil society organisations] were too much into dialogue advocacy and none would think that going to court can be a solution or can bring health justice,” said Hasifa Naluyiga, a senior advocacy officer with PATH, a CEHURD partner. “CEHURD opened everyone’s eyes and now many organisations are looking up to them to do what they do best.”

CEHURD is also preparing a future cadre of lawyers and activists eager to fight for the right to health. Through its volunteer programmes and its moot court competitions, the organisation has embedded an understanding of and respect for health rights in the upcoming generation of lawyers. An understanding and respect that they will carry into their work, wherever that leads them.

“It is remarkable that it is not just the professionals that are aware and follow up the right to health, but the fact that as a result of the moot court competition, the issue is also raised in Universities,” said Emmanuel Tumuhaise, who won CEHURD’s 2014 competition with another student. “This has played a key role in establishing the right to health, not just for students, but for society at large.”

And, of course, CEHURD will be there to continue to guide and expand these efforts.

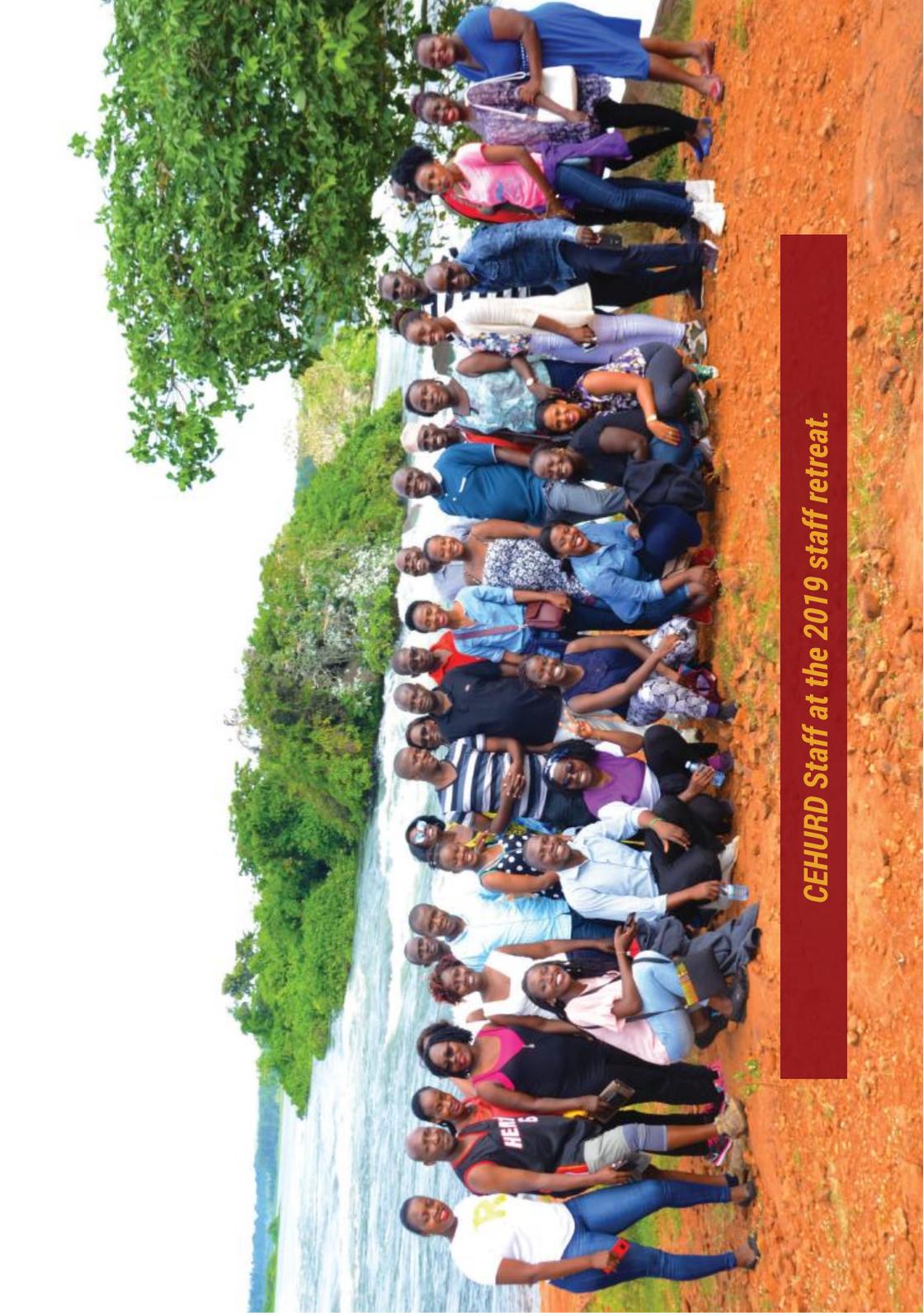
Even as CEHURD celebrates its first 10 years, the organisation recognises the immense amount of work that remains. For the pregnant women who continue to die from preventable reasons during delivery, for all the Ugandans still unable to

access critical medicines and for the marginalised and vulnerable across the country, CEHURD will continue what it has started and advance the right to health across this country.

“As a person who was there when this organization started, I am pleased with the work that has been carried out,” said Professor Ben Twinomugisha, the Chairman of the Board of Directors. “The right to health has been brought onto the agenda of government. The focus of advocacy, research and litigation in this country has been moved beyond civil and political rights violations, into the social and economic domain, including health and health rights. And in these 10 years, the level of awareness of the targeted communities about their health and human rights has been raised.”

OUR PROGRAMMES





CEHURD Staff at the 2019 staff retreat.

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