

Terrewode Women's Community Hospital



TWCH nurse Awor during health education session

Message from the Executive Director

Dear Reader

Welcome to our 12th edition of the newsletter which highlights developments at Terrewode Women's Community Hospital (TWCH), the only specialized health facility in Uganda for the management of obstetric Fistula.

In this newsletter, which also marks the end of our financial year, July 2021-June 2022, we bring you a variety of the developments with routine treatment of women and girls suffering from obstetric fistula ranking top priority.

A total of 103 patients received care from TWCH and 74 from partner health facilities in the quarter. Cumulatively, we have 572 patients treated out of our annual target of 600. TWCH treated 362 women and girls against an annual target of 400; while the partner hospitals dealt with 210 patients.

In the same quarter, a total of 121 survivors received our reintegration service. Cumulatively, we served 448 survivors against our annual target of 400. A few survivors received portions of these services which we provide according to the individual needs.

Additionally, the survivors undertook courses covering leadership, group formation and management, counseling, health education, gender, and human rights and their linkages to obstetric fistula and overall poor maternal health outcomes.

With the full opening of the economy, we intensified our patient identification outreach activities in Bukwo General Hospital, in Bukwo and Kapraron Health Centre IV in Kween District, sub region.

We also held a similar outreach session at Patongo Health Centre III in Agago District, Acholi Sub-region of northern Uganda.

This period also saw the revival of the five Teso pioneer Community Fistula Solidarity groups as part of our COVID -19 recovery program. Despite having been shaken by the pandemic, the groups have remained resilient and committed to the vision of TERREWODE. In this edition, we also bring the voices of the men who have joined our historical Obstetric Fistula Awareness and Advocacy Network (OFAAN) of vibrant community volunteers. A total of ten OFAAN members, 8 of whom were men, got recruited into the network.

You will also find a good read about our involvement in marking this year's International Fistula Day in Zombo, West Nile sub-region, located along the border with the Democratic Republic of Congo (DRC). Our emphasis in this year's celebration was on increasing the participation of men in the campaign to eliminate Obstetric Fistula.

Please, also hear from Margaret Arago, one of the pioneer survivors--turned obstetric Fistula change agent and the story of 18 year old, Gloria Cheptoyek.

We encountered a few challenges as some of our patients stayed longer at TWCH than expected. We are reviewing our strategies to prevent re-occurrence.

We believe you will have an enjoyable read with this issue of the newsletter!



Alice Emasu Seruyange, Founder and Executive Director of TERREWODE and TWCH

Teso Community Fistula Solidarity Groups Survive COVID-19 pandemic

The pioneer Community Fistula Solidarity (CFS) Groups from Teso sub region have stayed vibrant despite the two years of the COVID-19 pandemic. Admittedly, the pandemic shook the activities of all the five groups but did not destroy the vision and the spirit of members.

“Most of our members lost businesses, our group savings dwindled to the extent that our lending thresholds could not meet the groups’ demand for cash. However, this did not rob members of the groups’ vision, business knowledge and skills which is a treasure our communities acquired from TERREWODE,” said Joyce Mary Alalo, the Chairperson of Gengo Acwilili CFS Solidarity Group.

Alalo was speaking at a two-day reflection workshop we organized in Soroti to revive the momentum for Community Fistula Solidarity Groups in Teso sub region. The objective of the workshop was to reflect on the groups’ over 15 years-long journey with TERREWODE in the national campaign aimed at contributing towards the elimination of Obstetric Fistula and improvement of maternal health outcomes in Uganda.

Lambert Ejetu, the chairperson on the Music Dance and Drama Committee of the same group interjected, “Regardless of the restrictions on movement during Corona time, our group members continued to mobilize and educate, especially parents and school children, against child marriages and teen pregnancies’.

Joyce Aelo Ebamu, the chairperson of Diru Women’s Group said her group has a strong desire to extend the TERREWODE vision of eliminating obstetric fistula in the country.

She was all smiles and hailed TERREWODE for organizing what she termed as a networking forum for the Teso pioneer fistula activists.

“I recall back then when we started the war against fistula in the whole of Uganda. We are proud to have made progress and we are not about to give up as long as we live,” she said.

Though Diru members lost all their businesses as well as group savings during the pandemic, members are mobilizing family resources to resume active participation in their group.

Alice Agwang, of Amora Ican Group says there is no need for TERREWODE to worry about her group’s current struggles to restart because the members have hatched promising future strategies. She said, “We

are recruiting new members whose membership contributions will revive our savings group’s activities. We are also streamlining the group’s leadership and revising terms and conditions for lending and borrowing in order to avoid bad debts.”

These views were shared by all the participants who hailed TERREWODE for staying true to the fistula vision and maintaining contact with them throughout the pandemic period. The participants, who also toured the Terrewode Women’s Community Hospital (TWCH) for the first time, expressed happiness with the developments.

“God bless TERREWODE leaders, staff and partners. I can’t believe what I’m seeing. The ward, theater equipment, smart nurses and the high level of care for women who are lucky to come here for treatment is exceptional. During the time I got treated, this level of capacity was unavailable,” said Christin Aliano, member of Otieko Laka Group.

“We are reorganizing ourselves to pick up from where COVID-19 halted us. Do not bother to find business capital for us. The skills you provide are sufficient and we are using these to mobilize support from our community leaders and families,” Aliano said.



A cross-section of members of TESO pioneer groups during a reflection workshop

Fistula Survivor Turn into Maternal Health change Agents

"My journey to healing was rough! But TERREWODE became my road to hope," Margrete Arago recalls.

Arago is a resident of Abarilela sub-county in Amuria district and survivor of fistula. She once wrestled with the condition and came face to face with its associated stigmatization and ostracism from her community. It eventually drove her into poverty and attempted suicide.

"When TERREWODE identified me and started treating me, I got hope. I saw light at the end of the tunnel." Arago recounts a substandard life filled with loneliness and humiliation to the point that she couldn't attend village gatherings or church.

She was 30 years old when she got married and experienced four miscarriages, with the last one resulting in obstetric fistula. She was 47 years old when she had surgery and fully recovered.

"I was finally healed although I could not bear children anymore because of age," she narrates with mixed emotions of happiness and desolation.

Arago is now a maternal health change agent and owns a house in her village's trading center, which she established with the proceeds from her Flourishing catering business. She got into catering after completing the transformative reintegration program at TERREWODE.

Arago is also the chairperson of the women in her clan and the Abarilela community istula solidarity group, which she credits to TERREWODE leaders' training. After being treated and cured, fistula survivors are trained and reintegrated into communities as change instigators. This is aimed at strengthening maternal health as the survivors spread aware-

ness in their communities about the causes, prevention, and treatment options available for those weighed down by the Fistula. They are also armed with social entrepreneurship skills which inspire them to become self-sufficient and change agents.

"I started Fighting teenage pregnancies by sensitizing the parents and speaking against early child marriages. I am happy that I can notice a change in behavior among people."

Arago's undeniably strong spirit served as a fuel that led her and her group to a successful start. The Abarilela group orchestrated activities for up to 30 members. She successfully introduced savings and credit to support the income generating businesses for group members as an economic endorsement. As a result, members were saving up to Ushs 1,800,000 (about 480 US Dollars) annually before COVID -19!

The Abarilela group did not stop at that. A

few talented members of this group continued to use Music, Dance, and Drama as a powerful weapon to increase knowledge and awareness among the members of the community.

They were able to reach a large portion of Ugandans as they collaborated with renown and reputable celebrities from different regions in Uganda such as: Juliana Kanyomozi, a multiple award-winning Ugandan actress and pop musician well known among Western Uganda's decent musicians; Halima Namakula, a Ugandan musician, actress, entrepreneur and humanitarian from Central Uganda; and JM Kennedy, a pop singer from the West Nile. The group's triumph didn't stop there; they went to the extent of performing at Uganda's oldest cultural institution, most popular to tourists around the world.

Arago's group is among the 44 registered solidarity groups that TERREWODE has created.



Margaret Arago

For the last 15 years, TERREWODE has abetted the formation of groups with a membership of over 1,500 active survivors who are currently fostering maternal health across the three regions of her operations in Uganda.

"I cannot imagine how my life would be without this organization. Probably I would have died long ago because there is no way I would have been cured. To TERREWODE, I owe my life," – Arago said.

Young Women Flock TWCH for Care

Gloria Cheptoyek, 18, from Kapchorwa District, in Eastern Uganda, never wasted any moment to return to school soon after recovering from fistula treatment. Gloria was discharged from TWCH in April following a successful surgical treatment and subsequent reintegration program.

She thereafter rejoined Senior Four class at the Mountains of the Moon Secondary School in Fort Portal District of western Uganda in the second term.

She is among the 103 patients treated at TWCH this quarter, the majority of them being young women aged below 24 years. We also supported 74 other patients for treatment at partner health facilities elsewhere in the country through camps and in partnership with the Ministry of Health.

"It was a mentally and physically wrecking experience to me. I suffered discrimination and humiliation from friends and relatives. I knew I would never recover from urine flow because no one close to my family knew about its treatment," Gloria recounts. She had five months experience of living with a fistula before her father heard of free Fistula treatment at TWCH.



Gloria Cheptoyek

"I realized I was pregnant when a rapid pregnancy test was conducted after I missed my periods for three consecutive months. My mother was angry on receiving the results! She almost threw me out

of home to go to the home of the boy who was responsible for the pregnancy. My father was sympathetic and allowed me to stay at home until delivery time,” Cheptoyek narrates.

Amidst the restricted movements during the Covid-19 era, Gloria could not easily access a health facility when she experienced ‘false labour’ with intense contractions and pain. Two days later, with the help of boda- boda riders, Gloria was taken to Kapchorwa hospital. Unfortunately, it was too late for the health workers to save her baby. She was informed that her

baby had died in her womb and it required an emergency Caesarian section to save her life.

Gloria says despite the fact that she had spent a week of admission and recovery at the hospital, she only noticed constant leakage of urine two days later while at home after discharge from hospital. Gloria recalls the two-year closure of schools due to COVID-19 from March 2020 to February 2022 as the most painful life experience for her.

At the time, Cheptoyek was an ‘O’ Level candidate. She says the redundancy that followed the closure of schools coupled with peer pressures exposed her to unwanted pregnancy.

“The pregnancy experience and the rejection I suffered due to fistula made me determined to go back to school. I’m going to build on my previous learning experience to prepare and pass the forthcoming final examinations,” Cheptoyek narrates.

Men Declare War Against Fistula

“I’m happy to be part of TERREWODE. I have been hearing about the women’s fistula hospital in Soroti but I didn’t know the people behind it. I hope we shall today agree on ways for collaborations to support women from this community for treatment.”

In the past, I have been called to help patients of fistula at a point when they are contemplating committing suicide. I always intervened by giving encouragement for possible treatment in a surgical camp. But often this promise resulted in a long waiting time for care by the patients.” After learning about the quality care at TWCH, I have resorted to trusting the patients’ needs in their hands.

These were the words of Denis Loma, who was among a group of 15 men we supported to mark this year’s International Fistula Day celebration in Zombo District of West Nile sub-region. The annual event day usually marked on May 23 was marked this year on May 27, 2022 under the theme: “End Fistula Now: Invest in Quality Healthcare, Empower Communities!”

Prior to the celebrations, TERREWODE oriented Denis along with a team that comprised mostly Village Health Teams of the Ministry of Health local structure in Zombo. They were supported to take part in the procession march, aimed at increasing awareness and advocacy about obstetric fistula condition in the district.

TERREWODE’s focus this year was on increasing the participation of males in the national



Anita Kawooya Bangira (Centre), the state minister for health in charge general duties launches the National Obstetric Fistula Strategy 2020-2021-2024-2025 during the Fistula day occasion in Zombo

campaign to eliminate obstetric fistula and improve maternal health outcomes through massive community mobilization and strengthening collaborations with strategic community stakeholders and partners.

During the event we distributed awareness materials including annual calendars, T-shirts and Newsletters.

The Ministry of Health Commissioner for clinical and curative health, Dr. Amon Kaka Jackson, recognized TERREWODE for its dedicated efforts in fighting fistula.

“As a country we are happy that we have Terrewode Women’s Community Hospital which is filling the gap of long waiting for istula care by many mothers,” Jackson remarked.

Anifa Kawooya Bangirana, the Uganda state minister for health in charge of general duties, launched the National Obstetric Fistula strategy 2020/2021--2024/2025 during the event. She explained that besides the policy, the Ministry of Health is committed to prevent obstetric fistula and maternal deaths through massive upgrade of health facilities countrywide.

TERREWODE Programs Manager, Martha Ibeno, observed that empowering men to become part of the solution of obstetric fistula problem is strategic.

“Our focus on the VHTs, especially the men in Zombo, was deliberate. Capturing their voices on obstetric fistula sends a strong message to community leaders and policy makers, the majority of whom are men, to invest resources in maternal health,” Martha explained, “and thus, decision makers for health resources at all levels.”

She said TERREWODE’s participation at the event is very important because it strengthens the hopes of women and raises their confidence in seeking care for the fistula condition.

“For anyone who knows about our 20-year journey in fighting against obstetric fistula, our involvement in such national programs is a reassurance of commitment to the cause. It’s also a demonstration of the conducive working relations with the Ministry of Health, other local stakeholders and partners,” Martha explained.



Zombo Men during the procession

TERREWODE Expands the OFAAN to Bukedi Sub-region

Wanyama Bwako, 61, from Busia district, has worked tirelessly for over a decade in community rehabilitation programmes. He partook in activities regarding prenatal hygiene education in the community, as well as access to creditable antenatal care and proper nutrition. Recently, however, after being in contact with TERREWODE, he has become a strong supporter for women's access to efficacious fistula healthcare.

"Each time I look at a woman with fistula, I see a lot of resignation and pain," Bwako describes how the women's fear of humiliation keeps them isolated, and he therefore continues to persuade them to seek treatment in order to lead normal lives.

"It's not one of the most gratifying jobs if one is to think moneywise! But what is more gratifying than seeing a once depressed woman leading a happy life?" He poses a question.

Bwako is one of 10 active volunteers for the Obstetric Fistula Awareness Advocacy Network (OFAAN), who were recruited from the Bukedi subregion by TERREWODE. Bukedi subregion is the latest addition to TERREWODE's regions of program expansion.

The OFAAN is a pertinent workforce nourished by TERREWODE, consisting of eager community volunteers who collaborate with the Ministry of Health Village Health Teams (VHTs)



Bwako (Right) support TERREWODE staff with translations during the screening of patients in Masafu Hospital, Busia district



Fiona Atemo (Right), the physiotherapy nurse at TWCH talks to members of TESO pioneer groups.

to raise awareness and advocacy on obstetric fistula. OFAAN contributes significantly to heighten community awareness and advocacy, as well as mustering patients and referring them for potent care at TERREWODE. In the bargain, patients are also referred to commended treatment camps based on their individual treatment preferences

Each time TERREWODE holds an outreach in Busia district, Bwako actively participates in mobilization of women for the screening.

"Women play a big role in molding the family outlook. It's the women who knit the

different parts of the family together," Bwako explains.

The father of eight strongly believes that because women are the foundation of families, better health for them equates to sturdy and providential families.

"What even makes it harder is that I'm a man trying to convince women to get treatment."

Despite collaborating with TERREWODE and referring over 20 women from Busia, Bugiri, Namayingo, and Tororo to TWCH for fistula treatment, Bwako reports that persuading some patients to attend treatment is not always a piece of cake.

He characterizes mistrust as one of the barriers between patients and adequate maternal healthcare, "So you have to be patient and keep going back until they get a change of mind."

Bwako is a retired community-based rehabilitation officer who has served as a community mobilizer in various health facilities. His level of commitment to becoming a fistula health changemaker facilitated his visit to TWCH in May of this year, when he escorted patients from his district for treatment. His morale was boosted by his visit to the facility and he recognises that TWCH is the foremost specialized health facility he has ever observed in the country. Consequently, his trip only increased his desire to return to his district and identify more patients. Bwako takes pride in seeing women lead full lives.

"When a woman is sick, the family becomes sick, too! When the woman is happy, the entire family is also happy."- Wanyama Bwako

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