

NEWSLETTER

Child Help Tanzania - For Children with an Impairment



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Child-Help Tanzania to implement a "Buy A Shunt" Fundraiser Campaign, an initiative for children with Hydrocephalus



"Shunts have significantly contributed to saving the lives of many children with Hydrocephalus. Nowadays, the advancements in shunt technology and the effectiveness of shunt placement surgeries offer us great optimism. Child-Help Tanzania reports that the availability of shunts is often the primary challenge. The scarcity of treatment centers equipped to handle Hydrocephalus poses a significant obstacle in providing care for affected

children in regions where cases can emerge rapidly. To address these issues, Child-Help Tanzania has proposed to implement a Shunt Fundraiser that aims to raise..."

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The road that i have travelled, my testimony to new parents - “You are now in a secret world. You’ll see things you never imagined; ignorance, rudeness, and discrimination. Bu you’ll also witness so many everyday miracles, and you’ll know it. You won’t think a milestone is just a milestone. You’ll treasure things most wouldn't think twice about. You’ll become an advocate, an educator, a specialist, and a therapist, but most of all, you’ll be a parent to the most wonderful child”

Abdulahakim S. Bayakub

CHT Executive Director and Father

What our Partners are upto

Achievements by CHT partners contribute to fostering a healthier future generation.

Muhimbili Orthopedic Institute (MOI) starts off 2024 with a surgery camp for 50 children with Spina Bifida and Hydrocephalus.

20th April, 2024

50 children with Spina Bifida and Hydrocephalus received treatment at a surgery camp coordinated by MOI in collaboration with ASBAHT (Association for Spina Bifida and Hydrocephalus Tanzania) under the sponsorship of MO Dewji Foundation.

During an interview at the first phase of the surgery camp, Dr. Hamisi Shabani, expert neurosurgeon at MOI, said: "The total number of children in this program is 50. In this first phase of surgery, 25 children have undergone surgery and on May 4, 2024, the remaining 25 children will undergo surgery to complete the goals of this camp. These children are being operated on using advanced technology of open surgery, ETV, a procedure that allows a patient to return home within a few days after the surgery"



He mentioned that Spina Bifida and Hydrocephalus remain significant issues in this country, with statistics indicating that 7500 children are born with these conditions annually.

"Last year, MOI successfully treated 800 children with Spina Bifida and Hydrocephalus, highlighting the significant number of children still in need of care," stated Dr. Shabani.

Amina Ramadhan, the Project Coordinator at MO Dewji Foundation, said that this aid aims to provide children with the necessary treatment and hopefully help them return to their normal lives. "Every child's life is valuable. Even if the number of children exceeds 50, we will explore ways to support them despite setting a goal of 50 children this year. We are grateful to MOI and the Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT) for their collaboration."

MZRH partners with MOI experts for a five day Surgery camp.

13th April, 2024

Specialists from Mbeya Regional Referral Hospital and Muhimbili Orthopedic Institute (MOI) from Dar es Salaam joined forces to set up a surgery camp at MZRH. The camp lasted for five days from April 8th to April 12th.

The camp involved a number of cases including Spina Bifida and Hydrocephalus. On the first day, one of three cases was a 9-month old child with Spina Bifida who successfully underwent surgery that lasted for about an hour.



KCMC partners with experts from MOI for a surgery camp for 20 children with Hydrocephalus and Spina Bifida.

15-19 April, 2024

KCMC recently coordinated a surgery camp where their experts have partnered with neurosurgeons from Muhimbili Mloganzila Hospital and Muhimbili Taifa Hospital, including Dr. Hamisi Shabani, for a five day surgery camp. The camp reportedly treated 20 children with Spina Bifida and Hydrocephalus from Moshi.



KCMC Neurosurgery department receives donation of modern surgical equipment from WFNS.

22nd February, 2024

KCMC, through the department of Neurosurgery, have received a donation of modern equipment from the World Federation of Neurosurgical Societies (WFNS) in collaboration with the Barrow Neurological Institute. The devices, valued at 150 million shillings, aim to streamline surgical procedures for patients needing head surgery.



Neuro-surgeon Dr. Rabiell, receiving a donation of surgical equipment from World Federation of Neurosurgical Societies (WFNS) in collaboration with the Barrow Neurological Institute.

HoH Zanzibar's thriving relationship with NED Foundation

HoH Zanzibar works closely with NED Foundation by focusing on Physiotherapy programs.

House of Hope Zanzibar under UVVMW's supervision (Association for Spina Bifida and Hydrocephalus Zanzibar) have had great success with running their own Physiotherapy and Neurorehabilitation Program for the children.

HoH Zanzibar works closely with Ned Foundation from Spain who, from time to time, send their team of experts including neuropsychologists to visit the HoH for Physiotherapy and Neurorehabilitation programs.

Expert teams from NED Foundation have hosted a number of Physiotherapy and Neurorehabilitation programs throughout 2023 and following 2024 that involved sessions such as cognitive stimulation and physiotherapy evaluation.



In an effort to facilitate the ongoing rehabilitation program at the House of Hope, NED Foundation has donated two tablets and one Laptop which will be used for Neurorehabilitation workshops.

Also, a Clinical Review by Specialists from NED Foundation sets a pace for upcoming Rehabilitation workshops in 2024. A total of 22 children were reviewed at the House of Hope on 24th April 2024



Word of Appreciation from House of Hope Zanzibar

“We have seen a lot of changes from the children since we started the HOH with the help of Child Help and NED foundation. The doctors from Spain have been very helpful in the neurorehabilitation and cognitive stimulation program. We are expecting more activities coming forward. We conclude by thanking the whole team of CHT, NED Foundation and CHI for working and supporting us. May God bless you all.”

OUTETA, a new initiative by MWADETA for better treatment accessibility.

MWADETA forms a team of experts to reach and train referral hospitals, aiming to enhance the accessibility of SBH treatment services in Tanzania

OUTETA (Okoa Ubongo Team Tanzania) is a multidisciplinary team that deals with treatment and training about Hydrocephalus and Spina Bifida for health providers in referral regional hospitals in Tanzania, such as surgery, clinic, rehabilitation, and education on Continence Management.

OUTETA was founded on 10th August, 2023 by Dr. Gerald Mayaya (Neurosurgery expert at Bugando Referral Hospital), and Mr. Walter Miya (founder of MWADETA). OUTETA's primary goal is to train healthcare providers in referral regional hospitals around the lake zone on managing Hydrocephalus and Spina Bifida, safe anesthesia practices, among other areas.

Following extensive discussions on challenges faced by parents and referral hospitals like distance, financial constraints, patient overcrowding, and treatment delays, OUTETA was established to address these issues. The team aims to extend accessible services to 11 regions, with 6 of them located in the Lake zone.

OUTETA's three-month capacity-building program at Sekou-Toure Regional Referral Hospital aims to enhance the availability of SBH treatment services in Mwanza.

The decision for OUTETA to focus on the Lake zone primarily stems from the current situation at Bugando Regional Referral Hospital. Facing difficulties in treating SBH patients, OUTETA chose to step in due to various challenges, such as overcrowding, parents' struggles with treatment and follow-up due to distance and financial limitations, delays in treatment evidenced by statistical data indicating 20% receiving early treatment below 6 months of age and 80% receiving late treatment above 6 months, insufficient knowledge and skilled healthcare providers in managing SBH cases, and more.



The program consisted of comprehensive training and close monitoring of 50 trainees that included surgeons, anesthetists, nurses, social welfare, physiotherapists, and registrars.

The team from Sekou-Toure Regional Referral Hospital were very keen to learn how to manage Hydrocephalus and Spina Bifida cases. Following a five-day training session, the team started conducting surgeries under the guidance of the OUTETA team.

Over a span of three months, SRRH successfully operated on 26 children with Hydrocephalus and Spina Bifida. The initial 10 surgeries were conducted collaboratively by both OUTETA and SRRH teams for hands-on training. The remaining 16 surgeries were carried out by SRRH trainees with intensive supervision from OUTETA. Upon completion of the program, OUTETA confidently affirmed that SRRH was fully capable and skilled to offer comprehensive SBH treatment services.



OUTETA's intervention had specific purposes some of which are; to ease accessibility and distance for some parents, early treatment within 24 hours, to shorten process of surgery to 2-4 days, proper follow-up 6 times a year, early diagnosis of complication and intervention,

decongestion at the hospitals, to join efforts with the government in improving the treatment of SBH, and to reduce the morbidity and mortality rates.

Also, Bugando's Director Dr. Fabian A. Massaga had this to say: "At Bugando Medical Centre, we have observed a significant influx of patients with Spina Bifida and Hydrocephalus (SBH) across the Lake Zone region. Unfortunately, many of these patients face delays in seeking treatment due to distance and financial constraints, leading to various complications and post-surgery challenges. To address this issue, Bugando, in collaboration with MWADETA under the Neurosurgery Department led by Dr. Mayaya, initiated a capacity-building program at Sekou-Toure as a pilot project of OUTETA. This program aims to support the government's efforts in enhancing infrastructure and human resources at regional referral hospitals. By providing specialists to train doctors, surgeons, nurses, and anesthesiologists, our goal is to empower these healthcare professionals to effectively manage SBH cases within their respective regional hospitals. Through this initiative, we anticipate a reduction in delayed presentations, loss of follow-up, as well as morbidity and mortality rates among children in our community. We express our gratitude to the management of Sekou-Toure for their collaboration and support."

Representatives from Houses of Hope Kitongo and Nyegezi attended the program to ensure that all children under their care at the Houses of Hope, who were scheduled for surgery, were admitted promptly. They oversaw the registration process and procedures to prepare the pediatric wards for the children.

OUTETA expressed their gratitude by stating, "On behalf of Bugando Medical Centre Management, the Neuro Department, and Mwanangu Development Tanzania, we extend our thanks to CHILD-HELP for their financial support in conducting the OkoaUbongo (Save the Brain) Team Tanzania (OUTETA) training program. This initiative aims to enhance the management of Hydrocephalus and Spina Bifida cases, with the ultimate goal of reducing morbidity and mortality rates in Tanzania."

House of Hope Kitongo and the road towards Sustainability.

Income Generating Activities (IGA) set a new course for Kitongo's sustainability and youth empowerment.

At the House of Hope, the CHT team engages in mixed farming as part of their learning and development initiatives. They utilize cost-effective methods to raise livestock and implement permaculture to establish a self-reliant and sustainable agricultural ecosystem.

The majority of the parents in the residence are small-scale farmers. Besides providing for these parents and their children, the home aims to be self-sustaining and serve as a model for the parents. The farm yields food for the home, and any excess can be sold for additional income (IGA).

CHT gains valuable insights from these parents and reciprocates by assisting them in enhancing their farming and entrepreneurial skills. The ultimate objective for the House of Hope is to evolve into a fully self-sustaining residence.



Kitongo Village Water Well Project by Desk and Chair Foundation resolves water issues at Kitongo HoH.

One of the key goals set by Kitongo HoH for a sustainable home was ensuring a consistent and dependable water supply. Previously, Kitongo HoH had to purchase water that was sourced from the lake, which was both unsafe and unreliable. The objective was to invest in a water system that could offer safe and dependable water for all activities within the home.

After implementing the Water Well Project in KitongoSima village, the Desk and Chair Foundation extended their support by constructing a pipeline from the well and installing storage tanks for Kitongo HoH.



"We faced a significant water crisis where purchasing water was neither safe nor dependable. Thanks to the water project, we now have access to safe drinking water. Besides drinking, we will utilize it for watering our garden. Engaged in permaculture, we advocate for earth care, people care, and future care. Our cultivation includes food crops and fruit trees, all made possible by the generous donation from Mr. Sibtain through the Desk and Chair Foundation." said Sifa, Child-Help's information and Communication Officer.

Nyanguge Farm, Kitongo HoH's Latest Venture in Rice Farming.

Apart from cultivating crops and fruit trees within the home's compound, Kitongo HoH also oversees a plot not far from the home that is owned by CHT. This plot is dedicated to a rice cultivation initiative. The Kitongo team, along with the assistance of parents, volunteers, and experienced farmers, manages all these agricultural activities.



Kitongo HoH has outlined plans for 2024, with this project being one of many upcoming initiatives, such as maize farming. If successful, the project will enhance HoH's food reserves and create income opportunities.

The farm faced challenges when heavy rains caused flooding from the lake, affecting the crops. These setbacks not only affect the budget but also cause delays in meeting donors' expectations. The HoH team has urged donors and stakeholders to remain committed to the home, emphasizing the progress made towards achieving sustainability.

House of Hope Kimara is working towards expanding its capacity to accommodate more parents.

Under ASBAHT's and CHT's wing, House of Hope Kimara has been a safe haven for countless parents over the years and has been a bridge to treatment of the children with help from SBH stakeholders such as Muhimbili Regional Referral Hospital and donors.

As all other Houses of Hope, Kimara HoH aspires to evolve into a self-sustainable home. The goal is to expand beyond its current capacity to accommodate the increasing number of children requiring early intervention and care.

Mr. Nobert Kyando, the House of Hope manager, and a dedicated father to a 4 year old girl with Hydrocephalus, expressed his thoughts when asked about issues regarding the overall welfare of the Home.



Q: How do you plan to accommodate the rising number of parents visiting your house to oversee their children's treatment?

A: "To achieve the 2024 plan of continuing to support parents, we have informed the leaders of our ASBAHT association about this essential home service. The aim is to encourage parents to bring their children for treatment. Anticipating a significant turnout during a large treatment camp that we have planned with support from our stakeholders on April, all the parents and children are welcome at House of Hope Kimara, where we are ready to cater to their needs. To address the upcoming challenge, we have acquired additional necessities including ten (10) more mattresses to alleviate any accommodation issues for parents and children."



Q: What challenges do you face at the House of Hope?

A: "The main challenge we encounter in managing House of Hope services, in addition to caring for parents and meeting their needs during their stay, is the inability to financially support the high costs of their children's treatment. As House of Hope cannot fund the expenses for children requiring treatment, we must reach out to various stakeholders for assistance."

Q: Are there any updates on fundraising and engaging stakeholders? What steps are being taken to assist these parents in covering medical costs?

A: "At the HOH, many parents arrive unable to afford medical expenses. As a House of Hope, we've sought assistance from various stakeholders to support parents and children in covering the costs of tests and treatments. Expenses, like a CT scan for a child ranging from TZS 120,000 to TZS 310,000, and surgery costs between TZS 600,000 to TZS 1,200,000, are unattainable for most ordinary parents. Therefore, we have reached out to local stakeholders for financial aid. Thankfully, in the past two months, we have successfully assisted eight parents in covering all treatment costs. Our ongoing efforts have yielded positive results, as we have secured a local stakeholder, the MO FOUNDATION, to sponsor children's treatment from April onwards. We are still actively seeking additional stakeholders to support children and young people by providing Health Insurance and empowering them economically."

Q: What actions is the House of Hope team implementing to progress towards becoming an independent and self-sustainable home?

A: "We have been growing vegetables in our gardens and have recently started cultivating cassava in a separate area. We are excited to harvest cassava. The vegetable garden has been a great success, providing us with fresh produce for our home."



Q: What are your expectations for the near future?

A: *"We expect a significant rise in the number of parents from various regions in our country, attributed to a new partner assisting with our children's medical expenses. In addition, we aim to progress with plans for a collaboration to establish a rehabilitation center for the children. We are confident that the services at the House of Hope will improve from the initial stage, as we understand the necessity of enhancing support for parents with children facing challenges like Hydrocephalus and Spina Bifida."*

Q: How is the House of Hope handling the Continence Management Program?

A: *"Since engaging our trainer, the Continence Management service at Kimara HoH has become less challenging. Our plan to train parents and young individuals twice a month has been successful, with twelve children trained and four children returned to school after receiving training to overcome issues with bowel movements. Most of our assistants are from outside the House of Hope. The service remains crucial as we still hear about children struggling with these issues. However, those who have received help at HOH have returned to school successfully. Moving forward, it is vital to continue providing training and services at the House of Hope and to expand our team of trainers to support more children and youth in the coming year."*

Continence Management program

Feedback on Ongoing Continence Management training activities

Feedback from Hidaya's CIC workshop experience at Haydom Lutheran Hospital, Manyara

06-17 May, 2024

Haydom Lutheran Hospital hosted this year's first Continence Management workshop for Manyara region. This program, supported by Child-Help International and Haydom Friends Foundation, involved various activities throughout the week. These activities included theoretical and practical sessions on CIC and bowel washout, wheelchair maintenance by the team from CCBRT Moshi, mobility training, hygiene and wound care, education on Hydrocephalus and Spina Bifida, nutrition, and more. The trainers were Dr. Theresa-a German pediatrician, Francisca-a CIC nurse, Hendry Tlawi-the program coordinator, Hidaya Alawi-the national Continence Management Coordinator, and Gillil from the Arusha Skating Club.



Based on Hidaya's findings, out of the 70 parents contacted, only 40 attended, attributing this lack of participation to inadequate communication.

Hidaya observed that the parents who did participate in the training expressed great satisfaction with the educational sessions. Their responses during the activities were positive, displaying cooperation and understanding. The first week's assessment showed

fewer challenges compared to previous sessions, as parents now grasp the importance of CIC and bowel washouts, resulting in cleaner children with fewer wounds.

However, some children developed pressure sores due to factors such as not wearing shoes or socks, prolonged wheelchair use, or insufficient CIC routines. Some parents acknowledged neglecting their children's care at home, which became evident as ongoing challenges emerged.

"We have had another amazingly motivating follow up week with our SBH kids at Haydom Hospital Tanzania. Education, practical training, surgeries and lots of fun besides. 4 new wheelchairs have been distributed, 3 kids received orthopaedical surgeries to help them stand and prevent wounds, we have had a girls club and teaching girls to do catheterization alone, we have done a session on dental hygiene and nutrition with the kids - yes we also participated and brushed our teeth under the trees with them." said Dr. Theresa



When Hidaya was asked to express her views on matters concerning the Continence Management program, she responded;

Q: Do you encounter any challenges during the program that affect the smooth implementation of your training?

A: "Most parents attending continence management training come from villages and remote rural areas, requiring accommodation that is often costly for them. This situation leads parents to stay in wards at Haydom Lutheran Hospital, which offers accommodation during the program. These wards, originally for patients, become crowded with parents during these sessions. The need for a transit home in Manyara is evident. Thanks to Dr. Theresa's dedicated work in facilitating a "house of hope," project, this requirement may soon be fulfilled."

Q: What are your expectations on the ongoing House of Hope project?

A: “As per Dr. Theresa and the entire team at Haydom Friends Foundation, the project is progressing, with preparations underway to establish Haydom's House of Hope. We are optimistic that the project will be completed on schedule, ensuring a dedicated space for conducting resilience management training sessions when needed. This is crucial as the area currently used for training might be required for other medical programs due to Haydom hospital's upcoming renovation plans.”

Q: How has Continence Management training affected the SBH community throughout the years?

A: “In 2018 and 2019, during our participation in training programs, we encountered challenging situations where many children faced severe pressure sores and wounds due to poor hygiene and lack of continence management at home. The lack of information among parents about Spina Bifida contributed to these issues. Unfortunately, hearing about deaths caused by complications was a common occurrence during each program. Reflecting on our most recent program, significant progress has been made. Parents are more receptive and well-informed, leading to the implementation of continence management at home. As a result, children are in better health conditions, with only around three children experiencing mild pressure sores. Nowadays, most parents usually show concern about their children's participation in school and other social activities rather than socially isolating them.”

Q: What is the truth behind financial implications on parents being the root cause of early treatment and proper follow-up

A: “Most parents cannot afford reaching healthcare centers, and even if they do, they cannot afford accommodation expenses during and after treatment. **Nevertheless**, misinformation exacerbates these issues. Parents seeking professional guidance may receive inaccurate information regarding the actual costs of treatment, necessary medical interventions, available medical facilities, and proper care. We strive to educate parents and healthcare providers about the SBH community, aiming to spread this knowledge to various communities across Tanzania.”

Q: What is your advice to potential donor and stakeholders?

A: "To ensure that we provide comprehensive support to these children, it is crucial for stakeholders to collaborate, self-assess, and identify areas that hinder our progress and pose challenges to parents. By moving forward strategically, we can ensure that every bit of support is utilized effectively. We also call upon donors to contribute in any way they can. Besides financial aid, these children require access to education, mobility, and the opportunity to lead normal lives. There are numerous ways to ease the burden on those already making significant efforts to help. A special thanks to Haydom Friends Foundation and Dr. Theresa for their dedication to the SBH community in Manyara, particularly through the House of Hope project. For more information about the project and to make a donation, please visit their website at haydom-friends.org."



What our Government is upto

President Samia to Cover Treatment Costs for 100 Children with SBH

The President of the United Republic of Tanzania, Dr. Samia Suluhu Hassan, will sponsor the surgical and medical care for 100 children with Hydrocephalus and Spina Bifida at the Muhimbili Orthopedic Institute (MOI).

Today, on April 21, 2024, the Minister of Health, Honorable Ummu Mwalimu, announced this initiative during her visit to MOI. This decision follows the successful initial treatment of 25 of 50 children funded by the MO Dewji Foundation.

President Samia was moved by the plight of these children and has taken action to prevent any harm or disability resulting from delayed surgery for 100 more children.

The minister highlighted that the President's decision was influenced by information provided by ASBAHT (Association for Spina Bifida and Hydrocephalus Tanzania) on challenges faced by parents and guardians of approximately 200 children who require surgery but lack the financial means to cover the expenses.

In addition, Minister Ummu has praised the MOI institution for providing treatment for the children and the MO Dewji Foundation for funding the treatment of 50 children, while asking stakeholders to continue to come forward to help others.



"I urge my fellow parents not to hide children with Hydrocephalus and Spina Bifida, but to seek professional advice by taking them to the clinic," stated the Minister, emphasizing the importance of early treatment.



"Honorable President Samia has instructed me to secure funds for 100 children requiring surgery for Hydrocephalus and Spina Bifida conditions, fully covered by President Samia Suluhu Hassan." said minister Ummu.

Minister Ummu also mentioned that Professor Makubi, MOI's Director, should reach out to ASBAHT to identify these children. Within the next week or two, the ministry will allocate the necessary funds to cover treatment, surgery, and rehabilitation services for these 100 children, courtesy of our esteemed President, Dr. Samia Suluhu Hassan."

Buy a Shunt Fundraiser Campaign

CHT's initiative to help children with Hydrocephalus

Hydrocephalus is one of the most common disabling congenital defects, affecting around one in every 1,000 newborns in Tanzania. Regrettably, Infant Hydrocephalus is a significant contributor to mortality and disability in developing countries. However, owing to medical and technological progress in the last four decades, the projected life expectancy of children born with this condition has notably increased.



Shunts have significantly contributed to saving the lives of many children with Hydrocephalus. Nowadays, the advancements in shunt technology and the effectiveness of shunt placement surgeries offer us great optimism. More than half of infants who undergo shunt placement experience no complications and can keep the shunt for up to seven years or longer, requiring adjustments for physical growth.

Approximately 40% of children will eventually need a shunt replacement, and some may need more than two replacements. Sadly, a considerable number of children who do not receive shunt placement do not survive beyond their first year. However, those who undergo shunt placement have a higher likelihood of leading normal lives with typical abilities.



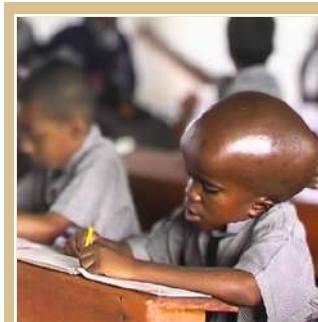
The shunt program began as a North-to-South initiative, engaging leading scientists to provide recommendations to Child-Help International regarding the shunts to be utilized. Access to shunts marks the initial stage towards receiving care and treatment. For 30% of infants born with hydrocephalus, a shunt is crucial for survival.

Pierre Mertens, the President and Founder of Child-Help International, sees the availability of shunts as a gateway to fulfilling the fundamental care requirements of children with hydrocephalus. By providing shunts and establishing connections with neurosurgeons in the Global South, it becomes feasible to support both distressed parents and their children.

Child-Help Tanzania reports that the availability of shunts is often the primary challenge. The scarcity of treatment centers equipped to handle Hydrocephalus poses a significant obstacle in providing care for affected children in regions where cases can emerge rapidly. Poverty and limited healthcare resources further impede access to proper care and early treatment. Additionally, the highest risk of shunt complications occurs during the child's first year, although complications can arise at any time. Occasionally, the shunt may malfunction or lead to an infection. Most individuals with a shunt require replacement at some stage in their life. Some may need multiple replacements, sometimes even several times within a year.

To address these issues, Child-Help Tanzania has proposed to implement a Shunt Fundraiser that aims to raise TZS 520,000,000 a year. With the price of a single shunt standing at TZS 130,000, Child-Help Tanzania aims to raise about 4,000 shunts a year.

The expected outcome is a decrease in morbidity and mortality rates among infants with Hydrocephalus, providing the disabled community with a chance for independent living, economic self-sufficiency, equal rights and status, and active involvement in social activities.



#GIVE LIFE



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