

sponsored content

PROGRAMMING TOOL. Researchers will also develop a programming tool that can integrate all the identified factors and give accurate predictions of likely disease occurrence in yet to be born infants, given mothers' exposure to certain conditions.



5

TARGET. The five-year project seeks to find out the causes and prevention measures of neonatal sepsis and hydrocephalus among infants.

NPA embarks on plan to control neonatal

Prevention measures. National Planning Authority is working with other partners on a five-year project to find out the causes and establish prevention measures of neonatal sepsis and hydrocephalus, among infants, especially in eastern Uganda, writes **Fred Wambede**.

The National Planning Authority (NPA) in partnership with Penn State University from the United States of America (USA) has embarked on a five-year project aimed at finding out the causes and prevention measures of neonatal sepsis and hydrocephalus among infants in the country.

Dubbed Predictive Personalised Public Health (P3H), the project started in October 2018 and is funded by the National Institute of Health based in USA.

The neonatal sepsis is the presence of blood infection in new-borns such as meningitis or pneumonia, often associated with fever.

Post infectious hydrocephalus on the other hand is water in the brain following neonatal sepsis.

Hydrocephalus condition can be due to problems such as brain tumours, trauma, birth defects, like spina bifida and malnutritions of the brain, among others.

Dr Abraham Muwanguzi, the Principle Investigator P3H project, says the project is aimed at developing policy interventions to address environmental related disease occurrences among infants.

"We want to identify the causes of neonatal sepsis and hydrocephalus in Uganda, specifically in the eastern and western regions," says Dr Muwanguzi. This is in order to come up with a comprehensive intervention to reduce infant mortality, which has stagnated in the past 20 years.

"The organisms causing the diseases affecting these infants are acquired before their delivery owing to factors related to environmental conditions, feeding, and genetics, among others," explains the doctor.

Planned outcomes

Project researchers will, among other things, test blood and cerebrospinal fluid (CSF) of infants who present with given conditions to establish the given diseases.

They also plan to test genes of infants and mothers to establish whether they harbour specific genes that could have predisposed the infants to infection.

Other actions will include analysing environmental factors such as rainfall, soil, and living conditions, to establish facts such as whether environmental factors affect incidence and location of neonatal sepsis and post infectious hydrocephalus.

OBJECTIVES

Project expectations.

According to Dr Abraham Muwanguzi, the Principle Investigator P3H, the project seeks to develop policy interventions to address environmental related disease occurrences among infants. The project, he says, also seeks to identify causes of neonatal sepsis and hydrocephalus in Uganda, specifically in the eastern and western regions.



Use of machinery for head scans

Investigators will also develop an affordable machine, in terms of cost, operation, maintenance and portability, that can be used for infant head scans to diagnose and follow up on hydrocephalus.

The investigators include engineers from Mbarara University, Penn State and Laden Universities.

Integrating causing factors

According to Muwanguzi, researchers will also develop a programming tool that can integrate all the identified factors and give accurate predictions of likely disease occurrence in yet to be born infants, given mothers' exposure to certain conditions. The P3H project is

going to further this work on refining the GIS map for Uganda earlier developed in the initial project phase by fusing satellite rainfall data with ground station data. Muwanguzi says this will facilitate more accurate predictions of the parameters being studied.

"The maps developed will accurately pinpoint the rainfall occurrence in Uganda at village level over a period of time. This data is helpful for planning in other sectors of the economy as well, especially agriculture and infrastructure," offers Muwanguzi.

The hospital administration at Cure is excited about the prospects of the project.

"This project will be a great step trying to save children born suffering from hydrocephalus and other conditions," says Dr Peter Ssenyonga, medical director of Cure Children Hospital.

Treatment. Mothers at Cure Hospital in Mbale District wait in lines to access treatment for their children suffering from hydrocephalus. PHOTOS BY FRED WAMBEDE



3,600

INFECTIONS. Estimates show that between 3,600 and 5,400 children in Uganda are born with or acquire hydrocephalus each year and facility is currently providing surgery for approximately 20-30 per cent of the annual need level.



The organisms causing the diseases affecting these infants are acquired before their delivery owing to factors related to environmental conditions, feeding, and genetics, among others. **DR ABRAHAM MUWANGUZI, THE PRINCIPLE INVESTIGATOR P3H PROJECT**

sepsis and hydrocephalus in infants

NEURO-SURGEONS CALL FOR NATIONAL DATABASE FOR CHILDREN WITH HYDROCEPHALUS AND NURAL TUBE DEFECTS

Neurosurgeons attached to Cure Children's Hospital in Mbale Town in Mbale District have asked government to generate a database of children with hydrocephalus and spina bifida in the country.

The medical director of the Hospital, Dr Peter Ssenyonga, says the generated data from different parts of the country would play a huge role in policy decisions by the government in as far as provision of health care is concerned.

Cure hospital is the only specialised neurosurgery children's hospital owned and administered by Cure International. The neurosurgical diseases treated at the facility include, hydrocephalus, neural tube defects, spina bifida, epilepsy, brain tumours, among others.

"This data can be of utmost importance because currently we do not have an accurate number of children living with such conditions in the country and yet they are vulnerable and require urgent health care," he explained.

He made the remarks last week during a visit to the hospital by a team of government officials from the National Planning Authority led by the executive Board chairperson, Prof Pamela Mbabazi Kasabiiti.

The field visit was based on the predicative personalised public health (P3H) project that is being implemented by the National Planning Authority to identify the causes of neonatal sepsis and hydrocephalus in Uganda specifically in the eastern and western regions. The team also visited neonatal ward at Mbale referral hospital and toured the neonatal unit.

Dr Kathy has implemented an approach to handling neonatal sepsis, which has reduced mortality in noenates at the hospital from 50 per cent in 2014 to 10 per cent currently. This needs to be replicated across the country

Witchcraft factor

Dr Ssenyonga said parents in different parts of the country with children suffering from hydrocephalus and spinal bifida, leave them to die in the villages because they think the conditions are caused by witchcraft.

"The parents think the conditions are not treatable and as a result, they abandon their children to die," he said.

Hydrocephalus is a condition in which there is an accumulation of cerebrospinal fluid within the brain, causing increased pressure inside the skull. It can occur due to birth defects and delayed poor treatment of infections, among others.

Dr Ssenyonga said that if the child with hydrocephalus is left untreated the head will continue growing to levels where nursing the child is very difficult. The brain growth is hindered affecting the child's development and ability to function and the raised pressure inside the head will lead to the child's death.

Over the past five years, Cure Uganda has annually performed an average of 1,300 neuro surgeries. In

2018, the hospital provided surgery for 951 cases of hydrocephalus.

About 70% of the monthly surgeries are hydrocephalus cases (with over 800 new cases per year), while spinal bifida, brain tumours and other neurological conditions account for the remaining 30%.

Cure Hospital is internationally recognised in handling brain and spina conditions and it trains surgeons from around the globe including in USA and Europe. To date it has trained 35 neurosurgeons.

Currently there are three neurosurgeons at Cure Hospital and three more will be joining at the end of 2019.

The hospital, however estimates that over 3,600 to 5,400 children in Uganda are born with or acquire Hydrocephalus each year and the facility is currently providing surgery for approximately 20-30 per cent of the annual need level.

Number raising

Dr Ronnie Mulondo, a researcher at the hospital, says the number of children with these conditions is on the rise. "The numbers are on the rise but we do not have the figures at the national level, which would help in effective planning," he said. Dr Mulondo said there is also need to create awareness among the parents, local leaders about the conditions, adding that they are treatable.

Ms Sarah Nahalamba, the Manager Social Sector Planning at NPA, said that mortality in the neonates has stagnated in the last 20 years.

"We want to identify the causes of neonatal sepsis such as meningitis or pneumonia, often associated with fever and post infectious hydrocephalus in Uganda, specifically in the eastern and western regions," Dr Mulondo said.

The executive director of National Planning Authority, Dr Joseph Muvawala, said it is their duty to have evidence so that government can come up with the right interventions.

"It's our duty to have evidence so that government can come up with good interventions," he said. He said they have started country wide tours to all government facilities to get clear information and data that will help in proper planning and budgeting.

"Most times, we have not been in the field and relied on inaccurate information," he said.

Dr Muvawala, said the authority is responsible for ensuring a sustainable and balanced national development by integrating economic, social and political dimensions of development with spatial and environment aspects.

"The institution is responsible for ensuring a sustainable and balanced national development in the country and we are working to achieve that," he said. Other functions of the authority include coordinating and harmonising development planning, monitor and evaluate public projects and programmes, advice the president on policies and strategies for the development of the country, among others.



Field visit. Dr Bernard Opar (2L), the Ministry of Health principal medical officer for Hospitals and Lower Level Facilities, Ms Agatha Babirye Kayemba (R), the NPA-P3H Project, Mr Moses Nyoto (2L), the Cure Patients Accounts officer and the mother of the child with hydrocephalus, pose for a photo during a field visit to a hydrocephalus survivor in Mbale District recently.



Surgery. Doctors at Cure hospital perform a surgery on one of the child with hydrocephalus last year.

sponsored content

COMMUNITY SENSITISATION. It is common for husbands to abandon their wives after a diagnosis of hydrocephalus and spinal bifida in their child. Which calls for community sensitisation to avert victimisation.



30%

TARGET. The number of children with Hydrocephalus who are able to access treatment through Cure Hospital ever year.

The struggle of parenting child with hydrocephalus

Ms Jackline Nandutu, a resident of Buwasa village in Buwasa Sub-County, Sironko District is happy that her child, Mark Magombe, who was born with hydrocephalus, is still alive.

Magombe was born 10 years ago with the disease that makes the head grow oversized due to low absorption rates of water in the body.

"I'm happy he is alive and okay. I named him after my father. My husband has refused to claim him as his child but he is my child and I love him," Ms Nandutu, a primary school teacher by profession, says.

Tearfully, Nandutu narrates how she has struggled to raise her son single-handedly from birth to date.

"My husband was not happy from the first day when he was told that the child had been diagnosed with the condition," she says, adding that she stayed alone at Cure hospital, when the child was being treated.

"There is still a lot of victimisation about the condition. What has kept me going is having faith and remaining strong," shares Nandutu.

Nandutu exemplifies the plight of most parents and victims of hydrocephalus and spinal bifida in the communities.

James Nazeba, another parent with child with the condition, says there is need for sensitisation because most people in the villages think it's a result of curse.

"This lack of knowledge results in stigma. Many parents with such children end up hiding them indoors hence denying them medical attention, leaving them to die," notes Nazeba.

Isaac Emurang, a social worker with Cure hospital, says it's common for husbands to abandon their wives after a diagnosis of hydrocephalus and spinal bifida in their child. Cure hospital conducts community sensitisation meetings in a bid to avert victimisation.

"We have also organised groups with mentors to help spread the right information on the conditions to prevent victimisation," says Emurang.

Dr Ronnie Mulondo, a researcher at the hospital, says there is an increasing number of children born with hydrocephalus in the rural areas. "But majority of them are hidden away in rural areas due to lack of knowledge and the means to seek treatment," he said.

Timothy C Erikson, the executive director of Cure hospital, says children, most of them born from poor families, had been neglected by their

Tour. Officials from NPA and Cure Hospital in Mbale District pose for a photo after touring the facility.

TREATMENT

Costs of surgery and treatment.

Treatment and surgery for hydrocephalus and spinal bifida costs Shs5.5m. However, patients contribute Shs950,000, which can be paid in instalments. "We are equipped to handle about eight cases per day but limited funding affects us tremendously," says Dr Peter Ssenyonga, the medical director of Cure Hospital.



families due to lack of money to seek treatment.

"Parents keep these children home due to lack of financial support," he explains.

The cost of surgery, treatment and hospital stay for hydrocephalus and spinal bifida patients is Shs5.5m. However, it is subsidised. Parents pay Shs950,000 which can be paid in instalments "If this hospital was elevated to national referral status and given more government support, it might be able to handle the overwhelming numbers," says Dr Peter Ssenyonga, the medical director of Cure hospital.

Dr Ssenyonga adds that the hospital could use government funding because donations alone are not enough. "We are equipped to handle about eight cases per day but limited funding affects us tremendously," he explains, also citing manpower shortage for specialists.

However, Prof Pamela Mbabazi, the chairperson of National Planning Authority, said there are procedures to be followed before the hospital can be granted a national referral status. "There are procedures, which must be followed before the hospital can be elevated," she says.

INCREASING NUMBER OF CHILDREN BORN WITH HYDROCEPHALUS

According to Dr Ronnie Mulondo, a researcher at Cure Hospital, there is an increasing number of children born with hydrocephalus, especially in the rural areas.

However, majority of such children, he says, are hidden away in rural areas due to lack of knowledge and the means to seek treatment.

Many of these, he says, blame

the disease of witchcraft thus by the time the children are taken to hospital the situation could have already worsened.

Reports by Cure Hospital and National Institute of Health indicate that between 3,600 and 5,400 children in Uganda are born with or develop the hydrocephalus condition every year.



NATIONAL PLANNING AUTHORITY AND MINISTRY OF HEALTH

NPA is working on this project with the Ministry of Health and together they are working on policies to inform development of guidelines on neonatal cases, a training

curriculum on neonatal handling for medical officers and policy briefs on neonatal sepsis. These will be informed by the research outputs from the project.

Courtesy visit. National Planning Authority executive board chairperson, Prof Pamela Mbabazi Kasabiiti shakes hands with one of Cure Hospital officials during a courtesy visit.