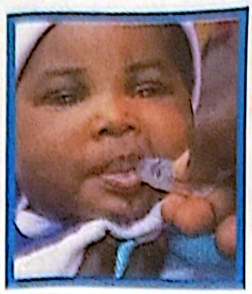
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Caregivers of children with Down Syndrome should boost their immune system by feeding them on lots of fruits and vegetables



2

Because of low immunity, precaution should be taken to guard against infections for example, pneumonia



3

Women who plan to have children at an advanced age should consult obstetricians to have prenatal diagnosis



DOWN SYNDROME: WHY PRENATAL DIAGNOSIS IS KEY

By Agnes Kyotalengerire

Christine Kazibwe keeps a close eye on her daughter while she is playing with her peers. When the girls walks out of the room, she follows her.

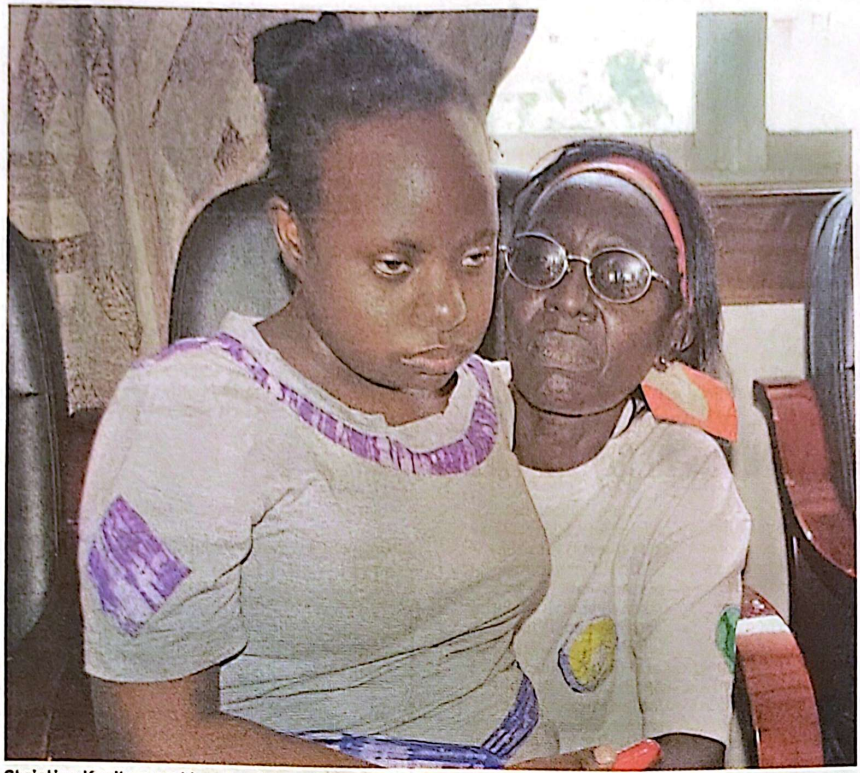
"Sometimes she is aggressive, so I have to monitor her closely so that she does not harm her friends," says Christine Kazibwe, 63.

Kazibwe, a mother of four says when she gave birth to her daughter 17 years ago, she did not notice any health defects. The baby looked normal and healthy.

However, two weeks later, she noticed her eyes did not look normal. Her pupils always dilated. When she consulted the nurses in a nearby clinic, they told her the child was normal.

However, the baby did not crawl, walk and delayed to talk," she says. She later learnt that her daughter had Down Syndrome after officials from the Uganda Down Syndrome Association visited and explained her daughter's health condition. They also encouraged her to join the association.

Wednesday is World Down Syndrome Day. The day, which is observed on March 21 each year, is aimed at raising public awareness about the condition.



Christine Kazibwe and her daughter who has Down Syndrome. The disease is hard to diagnose in Uganda

Watch out for

Dr Misaki Wayengera, a clinical geneticist at Makerere University College of Health Sciences, says children with Down Syndrome have small low set ears, short fingers, broad hands, moon-like face, big tongue, small mouth cavity, slanting eyes, flat nasal bridge, single, deep crease across the centre of the palm and large space between large and second toe.

The other key presentation is weakness of the muscles and when you hold the children, they fall to one side, he explains. He adds: "Under normal circumstances at the age of two months a child should be able to lift their head off the bed, something that children with Down syndrome cannot do

What is Down Syndrome?

Dr Daniel Tumwine, a paediatrician from Children's Clinic Naalya, describes Down Syndrome or Trisomy 21 as a chromosomal disorder.

He says it is caused by an error in cell division in the womb during conception, which results in an extra 21st chromosome.

A chromosome is a thread-like structure of nucleic acids and protein found in the nucleus of most living cells, carrying genetic information in the form of genes.

"There are normally 46 chromosomes in each cell, 23 inherited from the mother and the 23 from the father. When some or all of a person's cells have an extra full or partial copy of chromosome 21, the child presents with Down Syndrome," Dr Tumwine explains.

Statistics

Data from World Health Organisation (WHO) genomic resource centre shows that the estimated incidence of Down Syndrome is between 1 in 1,000 to 1 in 1,100 live births worldwide.

However, Dr Misaki Wayengera, a clinical geneticist at Makerere University College of Health Sciences, estimates that the genetic clinic that runs every Thursday at the pathology department in Makerere University Mulago hospital registers about two children with Down Syndrome every month.

Who is at risk?

Dr Jolly Beyeza, a senior gynaecologist/obstetrician at Mulago Hospital, says the chances of a woman delivering a baby with Down Syndrome increase with advanced maternal age usually from 35.

However, this does not mean that women above 35 cannot have normal children. It is just the case of increased risk, Dr Misaki Wayengera, a clinical Geneticist at Makerere University College of Health Sciences says. He adds that this does not mean that women who are below 35 cannot have children with Down Syndrome.

Dr Wayengera says as a mother advances in age, the quality of her ova also decreases.

"The ovary starts producing ova when a girl is born. This is unlike the case of the testes that only start producing sperms in adolescence. That means the ova age faster than the sperms. By the time a woman gets to 35 years, the quality of her ova has diminished," he explains.

Associated medical conditions

Children with down Syndrome grapple with a number of medical conditions.

According to Dr Wayengera, about 40% of the children born with the syndrome have an increased risk for congenital (born with) heart defects. Of those, 20% are in need of heart surgery.

Other medical conditions that may occur more frequently in children with Down Syndrome include thyroid problems, hearing, vision impairment intestinal abnormalities, seizure disorders, obesity, an increased susceptibility to infection and a higher risk of childhood leukaemia.

Additionally, Wayengera says such children suffer from frequent infections such as lower and upper respiratory tract infections.

He says they also delay to achieve growth milestones. They delay to sit, crawl, stand and are not fast learners.

Diagnosis and care

In developed countries, it is mandatory that women who have children in late age are screened for Down Syndrome during antenatal care.

The mother is advised to terminate the pregnancy if the baby is found to have Down Syndrome, which is not the case with Uganda.

A child suspected to have Down Syndrome should undergo a diagnostic test called Karyotyping.

Karyotyping is a process of arranging the chromosomes from a patient to see whether there is an increase in number.

Prenatal diagnosis critical

However, this test is not done in Uganda, Dr Wayengera advises women who plan to have children at an advanced age to consult obstetricians/gynaecologists for a prenatal diagnosis.

He says prenatal diagnosis will be based on the history and information present. For instance during antenatal care visits, if the woman is above 35, the doctors can watch out for the likelihood that she may get a child with the syndrome.

Treatment and management

The mental retardation that comes with Down Syndrome affects a child's speech and will require therapy to assist with expressive language.

Mike Alex Madit, the director of Uganda Down's Syndrome Association says the speech therapy intervention should be done between zero to five years or else the child will have difficulty catching up with speech, language and education becomes a challenge.

Dr Tumwine says the children with Down Syndrome have low immunity which puts them at risk of infections. He says precaution should be taken to guard against diseases for example ,pneumonia, ear infections among many. Caregivers should boost their immune system by feeding them on lots of fruits and vegetables.

They are happy children, but tend to be aggressive, especially when they are not getting their way.

Tumwine says the children have low IQ which means they get frustrated with complex tasks. The two characteristics call for the caregivers to be patient, understand their nature and not get upset with the children.

The children are prone to diabetes because they tend to be obese, so it is important to feed them on a healthy diet, says Tumwine. He adds that they should be active because they have a low metabolism rate.

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