HEARING IMPAIRMENT GENETIC STUDIES IN AFRICA (HI-GENES AFRICA)

The research vision of HI-GENES Africa is to become the network that facilitate diagnosis, care, and quality of life of people living with Hearing Impairment (HI), aligned with the international and local best standards. HI-GENES Africa aimed to provide the most efficient vehicle for capacity building that will fully engage the next generation of African scientists in precision medicine, through rigorous fellowship programs. This study is part of the Human Heredity and Health Consortium (H3Africa). The study will be performed by investigators at University of Cape Town (South Africa), the University of Yaoundé 1 (Cameroon), University of Bamako (Mali) and University of Ghana (Ghana).

WHY ARE WE DOING THE STUDY?

The reason for doing this study is to find the genes with changes that cause hearing impairment in people from Africa, and to better understand how these genes affect hearing in African populations. Knowing these genes can help doctors to improve their capacity to detect early and offer appropriate treatment to affected people, and to also give right advice to affected people or families.

HEARING LOSS - FACTS

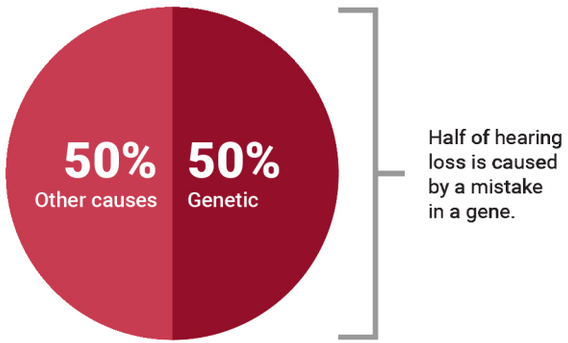
- About 1 in 6000 children are born with hearing loss worldwide and in Africa 6 in 1000 children are born with hearing loss.
- The severity of hearing loss differs amongst people.
- Can affect one ear (unilateral hearing loss) or and in others it can affect both ears (bilateral hearing loss).
- The extent of hearing loss differs from person to person ranging from mild hearing loss (some problems with hearing) to profound hearing loss (completely deaf).
- Sometimes even in the same family the degree of hearing loss can differ.

HEARING LOSS - CAUSES

There are many causes of hearing loss in new-borns. Some of the causes are:

- Maternal infection such as rubella and herpes simplex virus
- Premature birth
- Low birthweight
- Birth injuries
- Drug and alcohol use during pregnancy
- Maternal diabetes
- High blood pressure while pregnant (preeclampsia)
- Jaundice and Rh factor problems
- The baby no having enough oxygen (anoxia)
- **Genetics**

CAUSES OF HEARING LOSS



HEARING LOSS - GENETICS

Genetics or genes are each person's building blocks in the body that give instructions for all the structures in the body including the ear. We inherit our genes from our parents. Mistakes in these genes can lead to problems including hearing loss. 50% of all hearing loss is caused by a mistake in a gene. This hearing loss can be present at birth or develop later in life.

Genes that cause hearing loss can be inherited from one parent, both parents or the mistake can happen for the first time in the child. When inherited from parents, sometimes the parents carry the gene that causes hearing loss but they do not have any hearing problems. In this case the parents are said to be carriers. In some cases parents are affected and can pass on the gene to their children.

The hearing loss can be isolated, meaning that no other symptoms or affected body parts, or syndromic with other parts of the body being affected. Up to 75% of all hearing loss is isolated and the rest are a part of a syndrome.

- **In the black African population the genes responsible for the hearing loss is still unknown, making research very important.**

WHAT TO DO IF YOU SUSPECT YOUR CHILD HAS A HEARING PROBLEM

- If you suspect that your child might have a hearing problem, take them to the nearest clinic or doctor so that a hearing test can be organised.
- Do not wait long as the earlier the hearing problem can be confirmed the earlier possible treatment and the right school can be arranged for your child.
- If your child is diagnosed while still young there may be treatments such as cochlear implants, hearing aids and other hearing assistive devices that may be available which will allow for your child to have some speech and also chances of them going to a mainstream school increases.

Please feel free to contact the following person if you have any problems or questions about the research

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WHEN TO SUSPECT A HEARING PROBLEM IN YOUR CHILD:

0-3 Months	4-8 Months	9-12 Months
No response to sudden loud sound	Doesn't turn head towards sound	Does not respond to his name
No response to voices, music or sound even when sleeping in a quiet room	When in a quiet room, the baby does not change expressions at a voice or loud noise	Does not turn quickly towards a soft noise-maker or "shhh or shush"
Soft sounds do not soothe the baby	Does not like shaking a rattle, ringing bells or squeezing noise making toys	Does not have different voice pitches when babbling and also does not make different sounds
By 2 months the baby doesn't make vowel sounds like "ohh"	By 6 months does not try to copy sounds and also seems to hear some sounds but not others	When music plays the baby does not listen, bounce or sing along
By 2 months the baby doesn't become quiet at the sound of voices of people in the home	Has not begun babbling (baby talk) to self or back at others who talk to her	At 1 year does not say single words like: Mama, Papa, Dada
	Does not respond to a change in tone of voice such as "no"	At 1 year does not say the beginning of words
	Pays attention to vibrating noises (because they can be felt) more than regular noises	Does not understand words for common things in the house like "shoe" and expressions like "bye-bye" or commands like "come here"

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Genetic Medicine of African Populations

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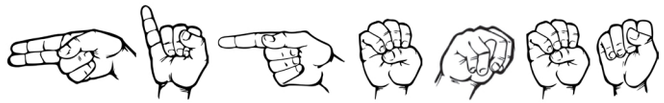
Hearing Impairment Genetics Studies in Africa



H I G E N E S

INFORMATION SHEET