HOPE ON THE HORIZON:
KITSO EXPLORES BIOMEDICAL & GENOMICS RESEARCH

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WAS EVERYTHING JUST A DREAM?

KITSO, LOVE, YOUR PORRIDGE IS GETTING COLD!

BUT IT WAS ALL SO REAL...

I HAD THIS GREAT DREAM. THE SUPERHEROES TAUGHT ME ALL ABOUT HEREDITY, GENETICS, AND DNA. OH, CAN I PLEASE HAVE SOME SQUASH?

SUPERHEROES? SORRY WE'RE OUT OF SQUASH.

THEY SHRUNK ME DOWN AND I WENT INSIDE THE HUMAN BODY. IT WAS AWESOME!

OH, DID YOU NOW?

YES! AND AUNTIE, I HAVE SOMETHING IMPORTANT TO TELL YOU. I WANT TO JOIN THE KALAHARI STUDY. SCIENCE IS COOL. I WANT TO HELP ELIMINATE HEY AND TB. LET'S GO TO THE CLINIC.

OK! FINISH YOUR PORRIDGE, THEN WE CAN GO.
YES, HE WOULD LIKE TO JOIN THE STUDY... WE'RE ON OUR WAY.

WHO'S XT7? MY NAME IS XUKURU. HAVE A SEAT. YOU MUST BE TIRED FROM YOUR JOURNEY.

AND HERE'S THAT SQUASH YOU WANTED EARLIER.

IT IS YOU!

30 MINUTES LATER...

(Number 24 please!)

KITSO THAT'S YOU. LET'S GO.
FOLLOW ME!

BRRRR... KGOSIGADI, IT FEELS LIKE WINTER IN HERE. LET'S USE YOUR POWERS TO WARM THINGS UP.

Huh? My name is MMA KALAFI. I'm a nurse and I'm going to explain the concept, but first let's take your vital signs.

AND I'LL SWITCH ON THE HEATER.

!!

SWISHHH!

DID YOU SEE THAT AUNTIE?

YES, THE SUN CAME OUT, WHAT A NICE DAY IT IS.

NO AUNTIE, KGOSIGADI DID IT WITH HER MAGICAL STICK!

NOW KITSO, THAT'S NOT EVEN MY NAME. LET'S GET ON IT WITH IT, SHALL WE.
I'm going to take your blood pressure.

Check your heart rate.

Temperature, weigh and measure you.

Everything looks good. Now let's talk about the study.

Let me start by saying that you can leave the study at anytime. Kitso, do you know what this study is all about?

To help the world learn how HIV and TB behave. Right?

That's right Kitso.

The study looks at your DNA and the DNA from lots of other children. Remember how you didn't have to start treatment until you were 10 years old?

Yeah?

Well, that's what's called a long-term progressor. Some children with HIV need treatment within the first few months of life.

We call those patient's rapid progressors.
WE WANT TO COMPARE YOUR DNA TO THEIRS AND SEE IF THERE ARE ANY DIFFERENCES THAT COULD HELP DEVELOP FUTURE TREATMENTS OR VACCINES.

OH! LIKE A GENOME-WIDE ASSOCIATION STUDY?!?

WE TALKED ABOUT IT IN GHANZI DISTRICT, REMEMBER?

OH KITSO, YOU'VE NEVER EVEN BEEN TO GHANZI DISTRICT.

WOW! THAT'S RIGHT, KITSO! HOW DID YOU KNOW THAT?
Anyway, let's talk about what enrolling in the study means for you. Every 6 months you come for a checkup and a blood draw.

If you join the study, we'll get just a little more blood on those days.

Oh, no extra punctures?

And no extra clinic visits?

No, there will not be any more blood draws than you get now, and all your visits will be on the same day as clinic.

That's great!

Now let's talk about consent. Consent means that you are giving permission for something. In this case, you are giving us permission to use your blood for studies.

It's very important to understand the following things before you give permission: why we're doing the study, what will happen during the study, and who will see your results. Now let's review those things...

Kitsi, this part is very important. Are you still with me?

Yes, but I'm a little...
HEY... UH... I MEAN XUKURI.

THANKS FOR THE SQUASH...SIR.

KITSO BECAUSE YOU ARE LESS THAN 21 YEARS OLD, YOUR AUNTIE WILL ALSO NEED TO SIGN A CONSENT FORM.

WHY? AUNTIE ISN'T PARTICIPATING IN THE STUDY.

BECAUSE YOU'RE NOT AN ADULT YET KITSO. AN ADULT WILL NEED TO GIVE US PERMISSION. YOU WILL ALSO GIVE US PERMISSION KITSO, BY SINGING AN ASSENT FORM, WHICH IS A CONSENT FOR KIDS.

BUT WHAT IF MY AUNTIE SAYS "NO" AND I SAY "YES"?

GOOD QUESTION. WE NEED BOTH YOU AND YOUR AUNTIE TO GIVE PERMISSION FOR YOU TO BE IN THE STUDY. WHAT DO YOU THINK KITSO?

WELL, WHAT ABOUT MY BLOOD? I KNOW AT THE CLINIC THEY MEASURE CD4 AND THE VIRUS, BUT NOW YOU'RE GOING TO DO EXPERIMENTS ON IT! WILL SCIENTISTS MAKE CLONES OF ME?
No Kitso, hahahah! Let me explain. For this study we use DNA in consent. That means scientists can use your blood sample, which we're going to store in a special safe building called a Biobank, for future studies that have to do with health.

Maybe in the future scientists will be able to make a vaccine for HIV and TB. It hasn't been possible yet, but your blood will be there for when they can do it. So, no, no one is going to clone you.

Phew! Any chance the scientists can give me some superpowers like yours?

No Kitso, we're only interested in making people healthy. And we all know that superpowers aren't real.

What do you say Auntie? I'm going to sign, "yes" on my assent form.

I'll only sign my consent form if the study is safe and important.

I do think the study is important. And I understand the procedures, the privacy, and who will see the results. Because of this, I'll sign "yes".

The study is very safe Mama. We won't do anything extra than what we would normally do during his check-ups, and we take many steps to ensure Kitso's privacy is respected. But I cannot decide for you if the study is important. You must decide that for yourself.

Excellent! Now let me go get the person who draws your blood.
Hello, my name is Dr. Mosenodi. It's time for your physical exam, Kitso.

No, you're Dr. Maboko. I just saw you walk through a wall! Such an imagination.

Agh! Wena, man! What's that my boy? anyways, everything appears normal. You're as strong as an ox.

I'm going to use a stethoscope to listen to your heartbeat and lungs. Have you had a cough recently? Any pain?

No, remember! I dodged the sickle cell when I was shrunk inside the blood vessel.

I'm going to use a syringe to draw blood. That's a fancy name for someone who draws blood.

Oh, I thought that's what vampires do?

Did you know we only need 3 teaspoons for the study? The rest is for your normal check-up labs.
OUCH! CAN'T YOU SHRINK THE NEEDLE WITH YOUR POWERS?

OH KITSO, I HAVEN'T EVEN STARTED YET...

OH...

ALL DONE!

WOW! THAT WAS EASY.

LET'S PUT THESE TUBES IN THE COOLER AND SEND THEM TO THE LAB AT THE UNIVERSITY OF MAMDIKOLI! KITSO, WHY DON'T YOU COME ALONG AND SEE ALL THE COOL TECHNOLOGY?

CAN WE, AUNTIE?

OF COURSE!

KITSO, THIS IS OUR LAB TECHNICIAN, TSEPO. HE'LL SHOW YOU AROUND AND TELL YOU ABOUT WHAT HE DOES WITH YOUR BLOOD. I HAVE TO GET BACK TO THE CLINIC.

WELCOME TO UM, KITSO!

MARANYANE! WHERE IS YOUR SUPERHERO OUTFIT?

HERE WE GO AGAIN...

I LIKE TO WEAR A WHITE COAT IN THE LAB.
SO, HERE WE GO. FIRST, WE SCAN YOUR TUBE TO KEEP TRACK OF THE SAMPLE. THEN, WE WARM UP YOUR SAMPLE IN A WATER BATH.

NOW THAT YOUR BLOOD IS NICE AND HOT WE'RE GOING TO SPIN IT IN OUR CENTRIFUGE TO SEPARATE THE DIFFERENT PARTS OF YOUR BLOOD.

THAT'S RIGHT KITSO, AND THAT'S WHERE WE GET THE DNA. WE'RE GOING TO ADD A FEW EXTRA INGREDIENTS CALLED REAGENTS TO BREAK UP THE CELLS AND ISOLATE THE DNA.

BEFORE SEQUENCING, WE ADD THE DNA TO THE FLUID/FLUID MIXTURE TO MAKE SURE IT'S THE RIGHT CONCENTRATION.

YOU DO THAT ALL BY YOURSELF, FOR EVERY PATIENT?

IT'S QUITE SUPERHUMAN, ISN'T IT?

NOW COMES THE EXCITING PART, KITSO: DNA SEQUENCING! WE PUT THE DNA INTO THIS MACHINE, WHICH CAN GIVE US A PRINT-OUT OF THE COMPLETE DNA CODE.

YOU MEAN IT CAN READ THROUGH ALL THE BOOKS OF THE DNA LIBRARY?

YES, KITSO! IT USED TO TAKE MONTHS TO READ THE DNA SEQUENCE, BUT WITH THE NEWER MACHINES WE CAN DO IT IN A MATTER OF HOURS.
Once the sequencing for all patients is completed, we can compare all their genes and look for new targets of medicines and vaccines! And that’s it!

That’s quite fascinating, but I think it is time for us to head back to the clinic.

Thanks, Maranyane!

I can’t believe so much work goes into these experiments.

It’s pretty impressive. I just wish there was some way I could help too!

I may have something in mind, come with me.

This is our community advisory board meeting in the clinic boardroom.

Is that Mr Bathoeng? He’s my school’s principal! Is he joining the study too?

Yes, that’s him, but he’s not joining the study. We have people from many different businesses and organizations here, representing the community to make sure the Kalahari study is acceptable to the public.

These stakeholders are part of the community in which the study is taking place: representatives of the media, religious groups, human rights organizations, and the health ministry, among others. But we don’t currently have anyone representing caregivers, Auntie...
You mean I could be on the community board?
If you would like to, we would be happy to have you.
Of course!

What about kids like me? Do we have a board too?

Why don't you look outside the window, Kitso.
Who are all of those kids?

That's the local teen club: a group that meets once a month to learn about science, life skills, and to have a community of people who take part in our clinic.

When can I join?

Let's see... how about now?

Can I, auntie?

Of course, dear.
DID YOU HAVE FUN AT TEEN CLUB?

YEAH! WE LEARNED ABOUT INTERVIEWING FOR JOBS. I MET A BUNCH OF COOL KIDS FROM GABORONE, AND THEY TAUGHT US ABOUT DNA, BUT I ALREADY KNEW ABOUT ALL THAT.

OH, FROM YOUR CLASSES AT SCHOOL?

NO, AUNTIE! I KEEP TELLING YOU: FROM THE SUPERHEROES?

OKAY, KITSO, WHAT SUPERHEROES?

EVERYONE WE MET TODAY. THEY'RE ALL SUPERHEROES LIKE I TOLD YOU!

I GUESS YOU'RE RIGHT: THEY ARE ALL OUR SUPERHEROES IN THEIR OWN WAY. THE THINGS THEY DO FOR US - CURING DISEASES, KEEPING US HEALTHY. DR. MOSENODI IS REALLY DR. MABOKO! ALL OF THEM ARE REAL SUPERHEROES WITH REAL SUPERPOWERS!

JUST LIKE YOU, KITSO, BY JOINING THIS STUDY.
GLOSSARY

SCIENTIFIC TERMS

**AUTOSOMAL RECESSIVE** - THE INHERITANCE OF A TRAIT OR A DISORDER IN WHICH TWO COPIES OF THE ABNORMAL GENE MUST BE PRESENT FOR THE TRAIT OR DISORDER TO DEVELOP.

**CD4 CELLS** - A TYPE OF WHITE BLOOD CELL THAT IS INVOLVED IN FIGHTING INFECTION. THESE ARE THE CELLS THAT ARE INVADED BY THE HUMAN IMMUNODEFICIENCY VIRUS AND ARE THE CELLS IN WHICH THE VIRUS REPLICATES.

**CCR5** - A PROTEIN ON THE SURFACE OF WHITE BLOOD CELLS THAT ACTS AS A RECEPTOR FOR HIV. HIV OFTEN USES CCR5 TO ENTER ITS TARGET CELLS. SOME INDIVIDUALS CARRY A MUTATION IN THE CCR5 GENE AND ARE RESISTANT TO HIV.

**MALARIA** - AN INFECTIOUS DISEASE CAUSED BY A PARASITE CARRIED BY MOSQUITOS. INDIVIDUALS WITH ONE COPY OF THE SICKLE CELL ALLELE MAY BE RESISTANT TO MALARIA.

**NATURAL SELECTION** - THE PROCESS WHEREBY ORGANISMS THAT ARE BETTER ADAPTED TO CHANGES IN THEIR ENVIRONMENT TEND TO SURVIVE LONGER AND PRODUCE MORE OFFSPRING. THIS THEORY WAS INTRODUCED BY CHARLES DARWIN.

**RECEPTORS** - PROTEIN MOLECULES ON THE SURFACE OF CELLS TO WHICH COMPLEMENTARY MOLECULES SUCH AS HORMONES OR ANTIBODIES RECOGNIZE AND BIND.

**SICKLE CELL** - AN ABNORMAL, CRESCENT SHAPED RED BLOOD CELL CONTAINING DEFECTIVE HAEMOGLOBIN. THESE SICKLE CELLS ARE CAUSED BY A HEREDITARY DISEASE CALLED SICKLE CELL ANAEMIA. SICKLE CELLS STRUGGLE DELIVERING OXYGEN TO THE TISSUES OF THE BODY.

**THE BLACK DEATH** - ALSO KNOWN AS THE BUBONIC PLAGUE, ONE OF THE MOST DISASTROUS PANDEMICS IN HISTORY CAUSED BY THE YERSINIA PESTIS BACTERIUM.

**ASSENT** - AN AGREEMENT BY AN INDIVIDUAL NOT COMPETENT TO GIVE LEGALLY VALID, INFORMED CONSENT.

**BROAD CONSENT** - WHEN PARTICIPANTS IN A MEDICAL STUDY GIVE CONSENT TO USE THEIR BLOOD FOR FUTURE STUDIES.

**CENTRIFUGE** - A PIECE OF LABORATORY EQUIPMENT, TYPICALLY USED TO SEPARATE FLUIDS OF DIFFERENT DENSITIES, BY SPINNING THE LIQUID SAMPLES AT HIGH SPEED.

**CONSENT** - AN AGREEMENT BY AN INDIVIDUAL THAT IS COMPETENT TO GIVE LEGALLY VALID, INFORMED CONSENT.

**DNA SEQUENCING** - THE PROCESS OF DETERMINING THE SEQUENCE OF NUCLEOTIDES WITHIN A DNA STRAND.

**FLUOROMETER** - AN INSTRUMENT USED TO MEASURE THE INTENSITY OF FLUORESCENCE TO DETERMINE THE CONCENTRATION OF A SUBSTANCE.

**LONG-TERM PROGRESSOR** - HIV-INFECTED INDIVIDUALS THAT TAKE A LONGER PERIOD OF TIME TO PROGRESS TO AIDS AFTER PRIMARY HIV-INFECTION.

**PHLEBOTOMIST** - PEOPLE WHO ARE TRAINED TO COLLECT BLOOD FROM PATIENTS FOR DONATIONS, TRANSFUSIONS OR MEDICAL TESTING.

**RAPID PROGRESSOR** - HIV-INFECTED INDIVIDUALS THAT QUICKLY PROGRESS TO AIDS AFTER THE PRIMARY HIV-INFECTION.

**REAGENTS** - EXTRA INGREDIENTS ADDED TO BLOOD TO BREAK UP CELLS AND ISOLATE DNA.

**STETHOSCOPE** - A MEDICAL INSTRUMENT USED TO LISTEN TO SOUNDS MADE WITHIN THE BODY SUCH AS A HEART BEAT.

SETSWANA TERMS

**WENA** - YOU
ACROSS
1. The process of passing traits and genetic characteristics from parents to their offspring.
4. A list of ancestors, a family tree.
6. One of two copies of each gene.
7. A coiled structure of DNA.
9. An infectious bacterial disease that can affect almost any tissue in the body, especially the lungs.
11. A measure of the number of viral particles present in an organism.
13. A diagram that is used to predict an outcome of a particular breeding experiment.
14. A jelly-like fluid that fills each cell and is enclosed by the cell membrane.
15. A lab test that measures the amount of CD4 cells.
16. A type of virus that infects and destroys the body's immune system.
19. An agreement by an individual not competent to give legally valid, informed consent.
21. The process at which proteins are created at ribosomes.
23. All the collective DNA contained in the chromosomes of an organism.
26. A change in the DNA code, an addition, a deletion or a substitution resulting in a different protein being produced.
29. When a certain trait is stronger than its opposite.
31. Several membrane-bound compartments with specialized functions that are present in the cell cytoplasm.
32. A membrane-bound sac in plant or animal cells that is involved in storage or transport of the products of metabolism.
33. Linear strands of DNA found in the nucleus of most living cells, carrying genetic information in the form of genes.
34. An abnormal, crescent shaped red blood cell containing defective haemoglobin, caused by a hereditary disease called sickle cell anaemia.

DOWN
1. Two different forms of a gene.
2. An allele/gene copy most likely to stay hidden in offspring.
3. Specific physical characteristics of organisms that make them unique.
5. An organelle consisting of a stack of flattened sacs that is involved in the modification and sorting out of proteins.
8. A thin biological membrane that separates the contents of the cell with the external environment.
10. A process involved with the synthesis of proteins where a DNA template is used to make RNA.
12. A building block of DNA.
13. Molecules composed of one or more chains of amino acids.
17. Ribonucleic acid.
18. An agreement by an individual that is competent to give legally valid, informed consent.
20. The set of observable characteristics of an individual resulting from the interaction of its genotype with the environment.
22. Small leukocytes (white blood cells) with a single round nucleus, occurring especially in the lymphatic system.
24. Protein molecules on the surface of cells to which complementary molecules such as hormones or antibodies recognize and bind.
25. An individual having two identical alleles of a particular gene or genes and so breeding true for the corresponding characteristic.
27. The building blocks of nucleic acids, RNA and DNA.
28. An infectious disease caused by parasites such as mosquitoes.
29. Part of every cell that carries information that determines the features or characteristics inherited from parents.
30. Extra ingredients added to blood to break up cells and isolate DNA.

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