

# Disability Guidebook

Summary descriptions of the most common disabilities in low- and middle-income countries



The logo for Kupenda for the children features a green silhouette of the African continent with a red heart in the center. The text "Kupenda for the children" is written in a serif font to the left of the map.

Kupenda  
for the  
children

The logo for Kuhenza for the children features a green silhouette of the African continent with a red heart in the center. The text "KUHENZA for the children" is written in a sans-serif font to the left of the map.

KUHENZA  
for the  
children

## About this Guide

### Authors

Kupenda for the Children is registered in the U.S. and Kuhenza for the Children is registered in Kenya. As our own nonprofit organizations, we report to our respective national governments, manage our own operational funds, and are overseen by our own boards of directors. Each year, Kuhenza and Kupenda collaboratively fundraise to support our joint projects. We have been co-designing and co-implementing disability programs and materials, such as this guidebook, since 2003.

### Purpose

The purpose of this guide is to provide caretakers and communities with a basic understanding of common disabilities, including their descriptions, causes, and recommended interventions. This guide is intended to be used by families and caretakers because it is focused on children with disabilities. However, much of the information included is relevant for adults with disabilities as well.

In low- and middle-income countries around the world, many people believe that a person with a disability has been cursed by God or witchcraft and is less than human. These negative beliefs often result in the neglect, abandonment, abuse, rape, or even murder of people with disabilities. However, when communities have a more accurate understanding of disability definitions, causes, and effective interventions, people with disabilities experience increased access to appropriate healthcare, education, and the love of community that all humans desire and deserve.

Unfortunately, many people in low-income countries have difficulty accessing accurate and simple information. This is due to associated costs, language barriers, or because most materials are highly technical and intended to be used by medical or disability professionals. In response, Kupenda and Kuhenza developed this guidebook. The pages that follow provide brief summaries of commonly encountered disabilities using language and graphics that a layperson can understand.

### Non-Diagnostic

The text, graphics, and images contained in this guidebook are for informational purposes only. None of the material in this book is intended to be a substitute for professional medical advice or diagnosis.

### Selection and Organization

Some of the disabilities highlighted in this guide fall under one or more of the following categories: intellectual, physical, sensory, mental, and emotional. Since some disabilities may be classified in more than one category, the disabilities are listed in alphabetical order, rather than by category.

The disabilities in this guide were chosen because they have a high prevalence in low-income countries. Some disabilities were also included because they are often misdiagnosed or misunderstood.

## Variability

Some people have more than one disability. Additionally, the symptoms and severity of each disability can vary significantly from one person to the next. It is important to understand that this guide provides a general overview of each disability and that no two people with the same disability are exactly alike.

## Intersectionality

In most cases, the individuals we've included as examples of people living with disabilities are of African descent. This is because the majority of Kupenda and Kuhenza's work takes place in Africa. However, it should be noted that each disability in this guide occurs among people of all races, ethnicities, and genders, unless otherwise specified.

## Disability Risk Reduction

The risk of having some of the disabilities listed in this guide can be reduced while others cannot.

For example, the chances of giving birth to a child with a disability can be reduced if the pregnant mother avoids exposure to anything that might cause infection (such as sleeping under a mosquito net to prevent mosquito-borne diseases like malaria).

To avoid complications during birth which may lead to disabilities, it is best for pregnant women to be seen for regular prenatal and postpartum appointments at a hospital or health facility. It is also important that they deliver at a hospital or health facility with medical equipment and trained staff to help deal with problems that may arise during labor and birth.

Immediately treating infections in infants and children can also reduce their chances of developing certain disabilities. In addition, parents and caregivers should make sure that children are regularly visiting their healthcare providers and sleeping under bed nets to prevent mosquito-borne diseases such as malaria. They should also ensure their children receive timely vaccinations as recommended by their doctor.

## Disability-Specific Interventions

Each disability described in this guide includes an "Intervention" section which is divided into two parts: Professional and Family / Community.

### Professional

Professional interventions include ways of supporting people with disabilities that must be prescribed by a medical professional, such as a doctor, nurse, therapist, or psychiatrist. A person with a disability in need of medical care should always be supported to access appropriate health professionals.

### Family / Community

Family / Community interventions describe ways in which the person with a disability can be effectively supported by those who are not medical professionals, such as parents, caregivers, siblings, friends, spouses, teachers, and neighbors. Many of the interventions in the Family / Community sections can also be implemented by the people with disabilities themselves..

## **Interventions Common to All Disabilities**

In addition to the interventions for specific disabilities that are described in this guide, there are also general interventions and support strategies relevant to all disabilities.

### **Family Support**

Disability impacts entire families, so it is important to establish support for everyone involved. Families of children with disabilities do better when they are connected to other families of children with disabilities. This allows them to help and learn from one another. Regardless of the type of disability, individuals with disabilities and their families should not go through the journey of disability alone. When looking for existing support groups or others to meet with, families can ask their community leaders, local schools, nonprofits, places of workshop, and medical facilities.

### **Professional Medical Diagnosis and Care**

If a person shows signs of a disability or illness, they should be taken to a medical facility as soon as possible. A diagnosis of disability should always be given by a medical professional. A medical professional can help the patient and his or her family to understand the disability and access related resources and services. It is also important for family members to learn how they can become involved in exercises and activities that help the person with a disability cope and thrive.

### **Impact**

We welcome feedback about your experiences with this guide so we may develop a better understanding of its impact and partner in its successful use. Please share your comments and recommendations by emailing us at [kupenda@kupenda.org](mailto:kupenda@kupenda.org)

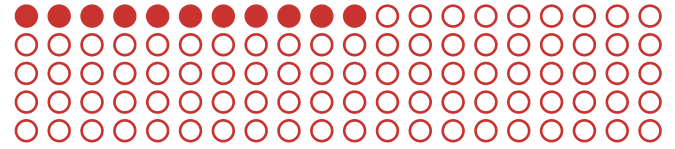


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# ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)



7 out of every 100 children  
18 and younger have ADHD.<sup>1</sup>

## DESCRIPTION <sup>2, 3, 4</sup>

Characterized by trouble focusing, difficulty controlling their actions, and seeming more active than others their age

## SIGNS AND SYMPTOMS <sup>5, 6, 7</sup>

Many people exhibit the symptoms below at one time or another, but people with ADHD have some or all of these symptoms, which may interfere with how they function socially, at school, or in a job.



EASILY DISTRACTED



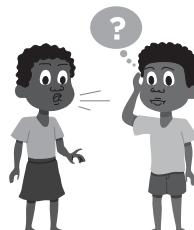
MOVE AROUND A LOT



MAKE SMALL MOVEMENTS WHILE SITTING



MAKE RASH DECISIONS



DIFFICULTY LISTENING



UNORGANIZED



COMPLETE TASKS LATE







FORGETFUL





TALKATIVE

## POSSIBLE CAUSES AND RISK FACTORS <sup>8,9</sup>

 <p><b>FAMILY MEMBERS</b> with ADHD</p>	 <p><b>DAMAGE</b> to certain parts of brain before birth</p>	 <p><b>PREGNANT MOTHER</b> <b>SMOKING OR</b> <b>DRINKING ALCOHOL</b></p>	 <p><b>PREMATURE</b> child is born too early</p>
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## INTERVENTIONS <sup>10,11</sup>

### Professional

 <p><b>MEDICATIONS</b></p>	 <p><b>REGULAR CHECKUPS</b></p>
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### Family/Community

 <p><b>LIMIT DISTRACTIONS</b></p>	 <p><b>PHYSICAL ACTIVITY</b></p>	 <p><b>KEEP REGULAR SCHEDULE</b></p>	 <p><b>DO NOT MOCK OR STARE</b></p>
 <p><b>DO NOT ABUSE OR PHYSICALLY PUNISH</b></p>	 <p><b>REWARD GOOD BEHAVIOR</b></p>	 <p><b>JOIN/FORM A SUPPORT GROUP</b></p>	



### SIMONE BILES <sup>12,13</sup>

Simone Biles is an Olympic gymnast who won hearts across the country with her 2016 gymnastic performance. Her powerful tumblers and gravity-defying beam routines set hearts ablaze and earned her the 2016 Olympic individual all-around, vault, and floor gold medals.

After the Olympics were over, leaked drug tests from the Olympic committee showed that Biles tested positive for methylphenidate. This drug is also known as Ritalin. It's prescribed to many individuals with attention disorders. As Biles stated, "I have ADHD and I have taken medicine for it since I was a kid. Having ADHD, and taking medicine for it, is nothing to be ashamed of [and] nothing that I'm afraid to let people know."

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

**NOTES**

1. "General Prevalence of ADHD," CHADD, accessed March 27, 2023, <https://chadd.org/about-adhd/general-prevalence/>.
2. "What is ADHD?" Centers for Disease Control and Prevention, last modified August 9, 2022, <https://www.cdc.gov/ncbddd/adhd/facts.html>.
3. "Attention-Deficit/Hyperactivity Disorder," National Institute of Mental Health, last modified September 2022, <https://www.nimh.nih.gov/health/topics/attention-deficit-hyperactivity-disorder-adhd>.
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9. "Attention-Deficit/Hyperactivity Disorder," National Institute of Mental Health.
10. "ADHD Treatment Recommendations," Centers for Disease Control and Prevention, last modified August 9, 2022, <https://www.cdc.gov/ncbddd/adhd/guidelines.html>.
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# ALBINISM

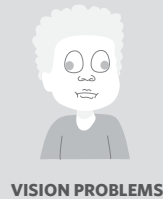
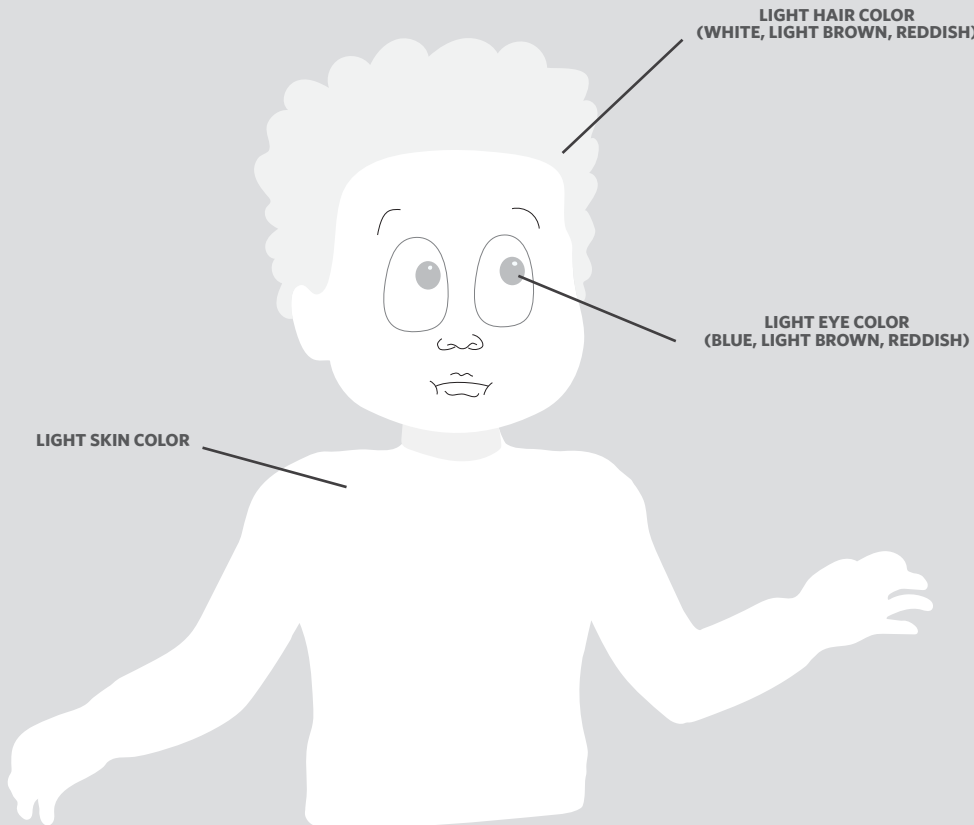


## DESCRIPTION <sup>4, 5</sup>

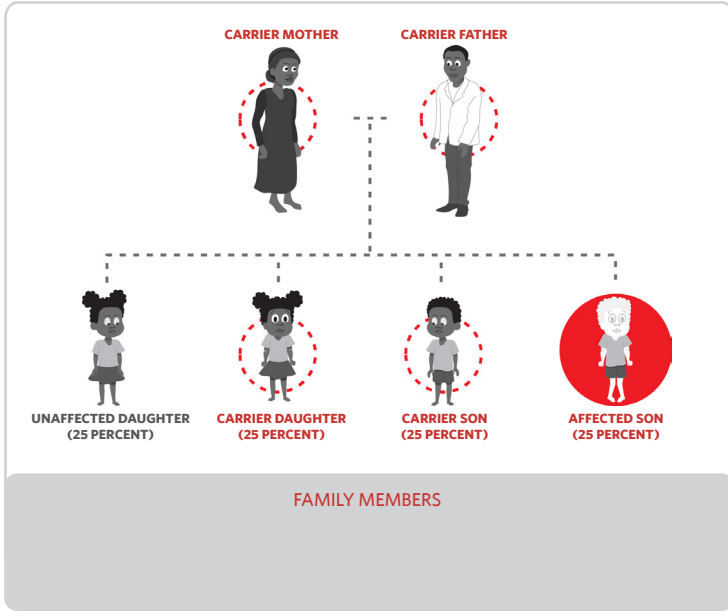
Little or no melanin (dark pigment), which is responsible for providing color to skin, hair, eyes, and the nerves in the eyes that are responsible for sight.

**1** out of every 17,000 to 20,000 people has albinism globally. In African countries, 1 out of every 5,000 to 15,000 people has albinism; though in some populations, it is as high as 1 out of every 1,000 people. <sup>1, 2, 3</sup>

## SIGNS AND SYMPTOMS <sup>6, 7</sup>



## POSSIBLE CAUSES AND RISK FACTORS<sup>8</sup>



- Males or females may have the condition equally.
- If a child has the condition and the parents do not, both parents carry the genes for the condition.
- A child may or may not have family members with the condition.



### REHEMA AND ALII

This brother and sister were born with albinism, although both parents are black. The father knew that he had a family history of albinism, but since he was educated about the condition, he did not view it as a problem. Today the children are enrolled in a mainstream school and protect their skin from the sun by wearing hats and sun lotions. Both of them are loved, well-cared for, and enjoy activities like any other child.

In other parts of the world, however, people with albinism live in dangerous circumstances. According to Amnesty International, in some parts of Africa, albino body parts are mistakenly thought to bring wealth and power. People with albinism are killed and their parts are sold for money. Others erroneously believe that sexual acts with a person with albinism will cure HIV and AIDS. To combat this negative stigma, albino rights groups are working to help others understand albinism and create a safer, more understanding environment.

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## INTERVENTIONS<sup>9,10</sup>

### Professional



EYEGASSES



SEE DOCTOR REGULARLY TO BE SURE THERE IS NO SKIN CANCER

### Family/Community



ENROLL IN MAINSTREAM SCHOOL



PROTECT SKIN AND EYES FROM THE SUN USING CLOTHING, HATS, SUNGLASSES, AND CREAMS



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH



JOIN/FORM A SUPPORT GROUP

### Kuhenza for the Children

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1. Justin R. Federico and Karthik Krishnamurthy, "Albinism," *StatPearls* (January 2023).  
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<https://www.un.org/en/observances/albinism-day>.
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10. "Albinism," Mayo Clinic.



# AUTISM SPECTRUM DISORDER



2 out of every 100 people have autism spectrum disorder.<sup>1</sup>

## DESCRIPTION <sup>2,3,4</sup>

Autism spectrum disorder (ASD) results in a broad range of characteristics that impact a person's social interactions, communication, behavior, emotions, senses, and thinking.

## SIGNS AND SYMPTOMS <sup>5,6,7</sup>

Many people exhibit the symptoms below at one time or another, but people with ASD have some or all of these symptoms, which may interfere with how they function socially, at school, or at work. A child with ASD may have:

**CHALLENGE WITH LANGUAGE OR SPEECH**

**STRONG REACTIONS TO STIMULUS**

**A PREFERENCE TO PLAY ALONE**

**DIFFICULTY EXPRESSING EMOTION**

**ISSUES IGNORING SOMEONE TALKING TO HIM/HER**

**DIFFICULTY KEEPING EYE CONTACT**

**A DISLIKE FOR BEING HUGGED**

**A DESIRE FOR CONSISTENT ROUTINE**

**EXTREME ATTACHMENT TO OBJECTS**

**REPETITIVE BEHAVIORS**

**UNUSUAL SLEEP PATTERNS**

**INAPPROPRIATE LAUGHING OR CRYING**


**LIMITED FOOD PREFERENCES**

**LOTS OF ENERGY OR MOVEMENT**


**LEARNING CHALLENGES**

**HIGH INTELLIGENCE**


## POSSIBLE CAUSES AND RISK FACTORS <sup>8</sup>



**BRAIN STRUCTURE**  
difference in brain structure and function from birth




**FAMILY MEMBERS**  
who have ASD




**POSSIBLE RISKS:**  
factors such as environment, infections, and parents' age

## INTERVENTIONS <sup>9,10</sup>


### Professional



**MEDICATIONS FOR SYMPTOMS**




**SPEECH THERAPY**

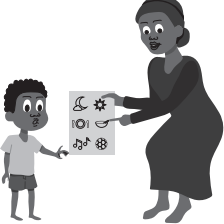


**SPECIALIZED EDUCATION**

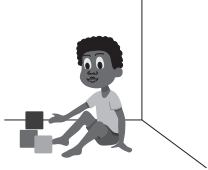
### Family/Community




**KEEP REGULAR SCHEDULE**




**COMMUNICATE WITH PICTURES OR GESTURES**




**HAVE A PLACE TO GO WHEN UPSET**




**LEARN FOOD PREFERENCES**




**KEEP FROM WANDERING TOWARD DANGER**



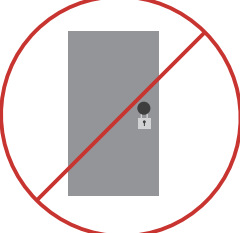
**DISTRACT FROM DANGEROUS ACTIVITY**




**DO NOT MOCK OR STARE**




**DO NOT ABUSE OR PHYSICALLY PUNISH**




**DO NOT LOCK IN ROOM ALONE**



**AVOID CAUSES OF NEGATIVE BEHAVIOR**



**REWARD GOOD BEHAVIOR**



**JOIN/FORM A SUPPORT GROUP**



### BRIAN

When Brian was starting to show signs of autism, his family believed he was deaf. This was because he didn't have speech and didn't respond to people when they spoke to him. However, they later observed him humming songs he had heard, revealing he could hear after all. By the time Brian was six years old, he was diagnosed with autism.

With support from Kupenda/Kuhenza and teachers that understood his autism, Brian had access to the tools he needed to progress. When he first started school, he could not communicate his needs, focus, or interact with others. Now he can gesture to interact with others, has improved in his concentration, and enjoys playing with his peers.

Kuhenza/Kupenda also counseled Brian's family to help them understand his autism. Today they accept him for who he is and are very grateful for all he is able to do.

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**NOTES**

1. "Autism Spectrum Disorder (ASD)," Centers for Disease Control and Prevention, last modified March 25, 2020, <https://www.cdc.gov/ncbddd/autism/facts.html>.
2. "Autism Spectrum Disorder," Centers for Disease Control and Prevention.
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10. "Autism Spectrum Disorder," Centers for Disease Control and Prevention.



# BLINDNESS AND VISUAL IMPAIRMENT



3 out of every 10 people have a visual impairment and at least half of these cases are preventable.<sup>1,2</sup>

## DESCRIPTION<sup>3,4</sup>

People with complete blindness cannot see anything, including light. Others might have some vision but not enough to successfully do daily activities at home, school, or work.

## SIGNS AND SYMPTOMS<sup>5,6,7</sup>

(People with blindness or visual impairment have some or all of these signs and symptoms.)



EYES DO NOT FOLLOW OBJECTS OR PEOPLE AS THEY MOVE



LOOK AT THINGS WITH ONE OR BOTH EYES PARTIALLY CLOSED



EYES MAY SEEM TO LOOK IN DIFFERENT DIRECTIONS FROM ONE ANOTHER



WHITE OR GRAYISH WHITE COLOR IN THE MIDDLE OF THE EYE



EYES THAT MOVE QUICKLY FROM SIDE TO SIDE OR UP AND DOWN



EYE PAIN

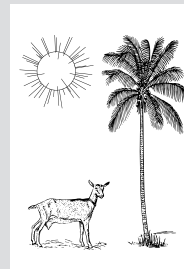


WATERY EYES



HEADACHES

## EXAMPLES OF WHAT A PERSON WHO IS BLIND OR VISUALLY IMPAIRED SEES OR DOESN'T SEE<sup>8</sup>



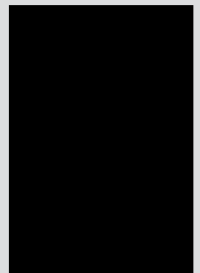
CHILD WITH NO EYE PROBLEMS



PARTLY BLIND









ONLY SEES LIGHT

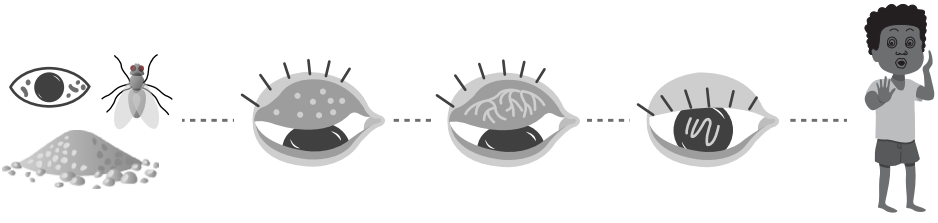


COMPLETELY BLIND

## POSSIBLE CAUSES AND RISK FACTORS <sup>9, 10, 11</sup>

 <p><b>INFECTION</b> like trachoma, measles, herpes, conjunctivitis, and parasites</p>	 <p><b>DRY EYE</b> from lack of vitamin A found in milk, eggs, vegetables</p>	 <p><b>DAMAGE TO EYE</b> from chemicals or object</p>	 <p><b>DIABETES</b> inability to process sugar or starch without artificial help</p>	 <p><b>PARASITES</b> that cause conditions like river blindness</p>	 <p><b>FAMILY MEMBERS</b> with blindness</p>
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**THE LEADING CAUSE OF BLINDNESS WORLDWIDE**



1. FLIES (CONSUMING FECES OF INFECTED PERSON), DIRTY OBJECTS, OR AN INFECTED PERSON BRINGING BACTERIA TO EYES
2. EYE SWELLING
3. SCARS INSIDE THE EYELID
4. SCARS CAUSE EYELASHES TO SCRATCH THE EYE
5. BLINDNESS

Trachoma is a disease that can cause blindness and visual impairment in about 1.9 million people every year. Poor communities in rural areas of Africa, Central and South America, Asia, Australia, and the Middle East are most affected.

Poverty, poor sanitation habits, and overcrowded areas are common factors that encourage the spread of the disease.



### ATHUMAN

Athuman is a 12 year old boy who is hard of hearing and has a visual impairment. He currently attends Kwale School for the Deaf. He understands tactile sign language and can follow instructions. He can also walk alone around the classroom and to the toilet. He is doing well and his teacher is planning to move him to the pre-vocational class.


At school, Athuman also participates in sporting activities such as acrobatics, track and field, and walking with guidance. He also took part in the national games and has been featured on the Kenyan television show "Able Differently."

At home, he likes discovering new places through touch and even climbs very tall trees. Although his parents separated for a while, they have now reunited. They love and accept their son, as does his whole community.

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## INTERVENTIONS <sup>12, 13, 14</sup>

### Professional



**SURGERIES**

**SPECIALIZED EDUCATION**

**GLASSES FOR THOSE WHO HAVE SOME SIGHT**

### Family/Community



**CANE OR STICK TO HELP HIM/HER GET AROUND**

**HELP FROM ANOTHER PERSON TO GET AROUND**

**HEALTHY DIET**

**JOIN/FORM A SUPPORT GROUP**

**NOTE:** When interacting with the person who is blind, tell him/her what is happening around him/her and what you are going to do that involves him/her. (Example: Tell him/her that you are going to wipe his/her nose.)

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## INTERVENTIONS CONTINUED . . .

## Family/Community



DO NOT MOCK OR STARE

DO NOT ABUSE OR  
PHYSICALLY PUNISH

## NOTES

1. "Blindness and vision impairment," World Health Organization, last modified October 13, 2022, <https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment>.
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14. Rogers, "World Sight Day."



# BRITTLE BONE DISEASE (OSTEOGENESIS IMPERFECTA)



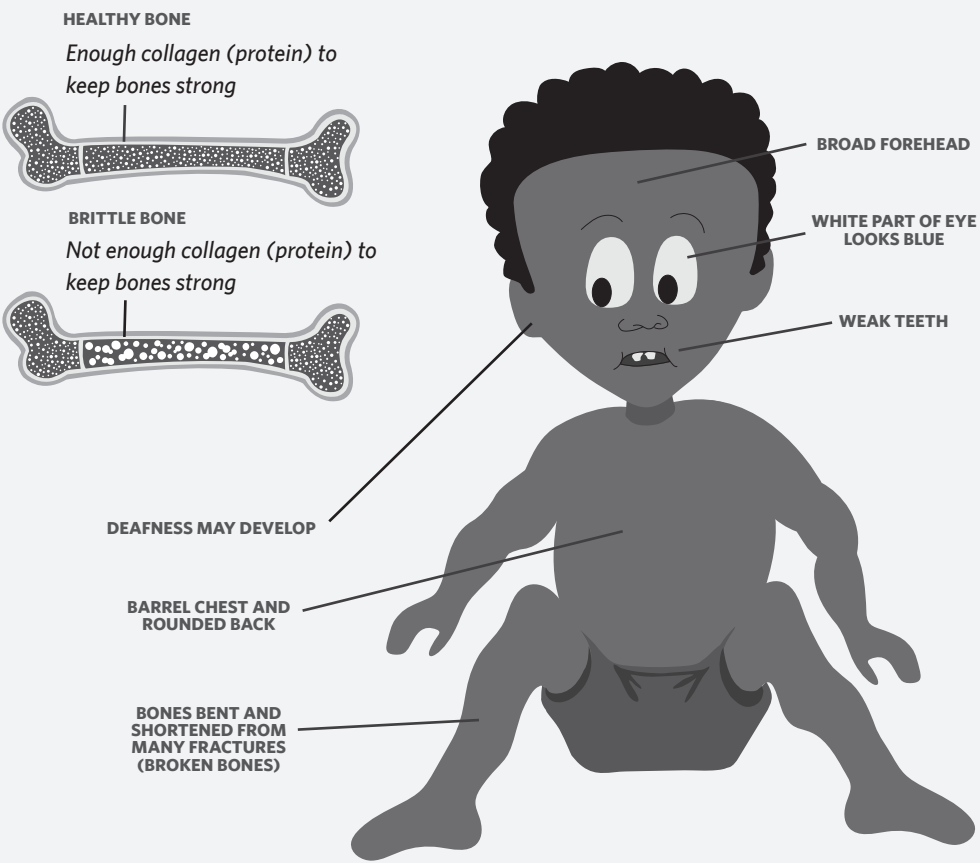
1 out of every 10,000 people have brittle bone disease.<sup>1</sup> One open dot = 10

## DESCRIPTION<sup>2,3</sup>

Brittle bone disease is a genetic disorder in which children are born with little to none of the proper protein (collagen) needed for healthy bones. This causes bones to be weak and break with little to no cause.

## SIGNS AND SYMPTOMS<sup>4,5,6,7</sup>

People with this condition may have some or all of these signs and symptoms.



**BROKEN BONES WITHOUT CLEAR CAUSE**



**DELAYED SITTING, STANDING, CRAWLING, AND WALKING**



**HEARING LOSS (50%)**



**SHORTER THAN OTHERS THEIR AGE**

## POSSIBLE CAUSES AND RISK FACTORS <sup>8,9</sup>



**FAMILY MEMBERS**  
with this condition (75%  
chance of child having it)



**DAMAGE TO THE GENES**  
information passed from  
either parent to the child  
during formation

## INTERVENTIONS <sup>10,11,12</sup>

*Note: There is no cure for this condition, but there are some interventions that can improve the life of a person with brittle bones.*

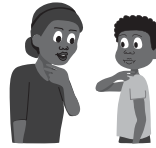
### Professional



**MEDICATIONS FOR SYMPTOMS**



**SURGERIES TO SUPPORT BONES**



**SPEECH THERAPY**



**PHYSICAL THERAPY**

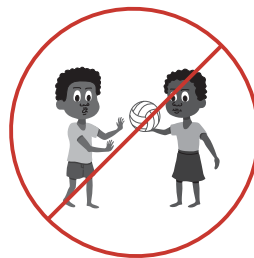
### Family/Community



**TAKE TO DOCTOR WHEN THERE ARE BONE BREAKS**



**HEALTHY DIET**



**AVOID ACTIVITIES THAT COULD CAUSE BONE BREAKS**



**DO NOT MOCK OR STARE**



**JOIN/FORM A SUPPORT GROUP**



**DO NOT ABUSE OR PHYSICALLY PUNISH**



## CARLOS

Carlos is a young man living with brittle bone disease. Although he has five siblings, he is the only one with this condition.

His parents were concerned when Carlos experienced his first broken bone at one month old. As he was growing up, Carlos continued to break bones easily while playing or even sleeping.

When he reached school age, he attended a mainstream school nearby. During his time there, he experienced several breakages which forced him to spend time in the hospital.

Despite these challenges, Carlos was still able to attend a mainstream high school. Afterwards, he went on to complete a computer course.

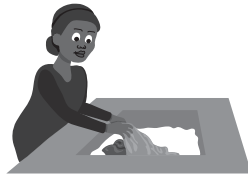
Due to the many breakages he experienced at a young age, Carlos is shorter in stature than the rest of his family. However, this did not limit his ability to receive an education and dream about his future!

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## Family/Community (For those who are unable or have difficulty moving on their own)



**CHANGE THEIR POSITION OFTEN**



**ENSURE THEY HAVE CLEAN CLOTHES**



**BATHE THEM AFTER SOILING THEMSELVES**



**USE TOILET ADAPTATION**



**PROVIDE PAMPERS (NAPKINS)**



**PROVIDE ASSISTANCE DEVICES**

## NOTES

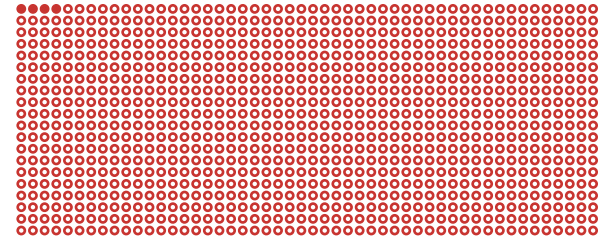
1. Surabhi Subramanian et al., "Osteogenesis Imperfecta," *StatPearls* (February 6, 2023). <https://www.ncbi.nlm.nih.gov/books/NBK536957/>.
2. Subramanian et al., "Osteogenesis Imperfecta."
3. David Werner, *Disabled Village Children* (Berkeley: Hesperian Health Guides, 2018), 126.
4. Subramanian et al., "Osteogenesis Imperfecta."
5. Werner, *Disabled Village Children*, 126.
6. Afsaneh Khetratal, "Types of Osteogenesis Imperfecta (OI): Brittle Bone Disease," News Medical, last modified December 22, 2022, <https://www.news-medical.net/health/Types-of-Osteogenesis-Imperfecta-%28OI%29-Brittle-Bone-Disease.aspx>.
7. "Osteogenesis Imperfecta: Overview," National Institutes of Health: Osteoporosis and Related Bone Diseases National Resource Center, last modified July 2019, <https://www.bones.nih.gov/health-info/bone/osteogenesis-imperfecta/overview>.
8. Werner, *Disabled Village Children*, 126.
9. "What Causes Osteogenesis Imperfecta (OI)?" National Institutes of Health, last modified December 20, 2021, <https://www.nichd.nih.gov/health/topics/osteogenesisimp/conditioninfo/causes#:~:text=Mutations%20in%20several%20genes%20can,collagen%20or%20too%20little%20collagen>.
10. Werner, *Disabled Village Children*, 126.
11. Subramanian et al., "Osteogenesis Imperfecta."
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# CEREBRAL PALSY

## DESCRIPTION <sup>2</sup>

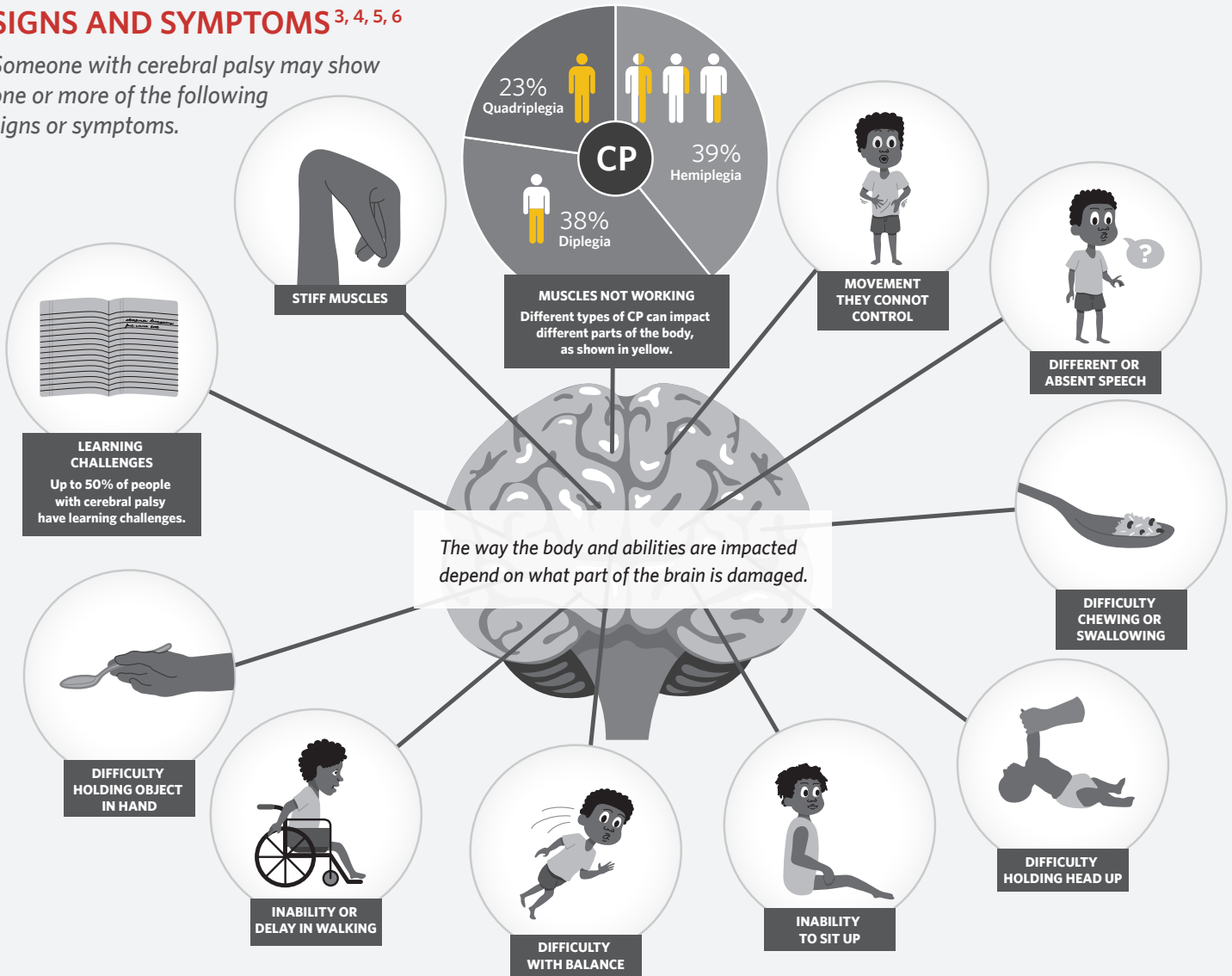
Cerebral palsy (CP) is caused by brain damage to children below the age of 5 that impacts their muscles and ability to move and balance. The damage to the brain does not get worse over time, but new challenges may occur as they age.








**1-4** out of every 1,000 people have cerebral palsy.<sup>1</sup>

## SIGNS AND SYMPTOMS <sup>3, 4, 5, 6</sup>

Someone with cerebral palsy may show one or more of the following signs or symptoms.




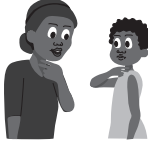



## POSSIBLE CAUSES AND RISK FACTORS 7, 8, 9


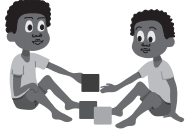




 <p><b>DAMAGE</b> to certain parts of brain before or during birth or in early years</p>	 <p><b>OXYGEN DEPRIVATION</b> before or during delivery or from other conditions</p>	 <p><b>PREMATURE BIRTH</b> child is born too early</p>	 <p><b>INFECTION</b> from diseases that damage the brain</p>	 <p><b>INJURY</b> to the brain from accidents</p>
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## INTERVENTIONS 10, 11, 12, 13

**Professional**



 <p><b>MEDICATIONS</b></p>	 <p><b>SURGERIES</b></p>	 <p><b>PHYSICAL THERAPY</b></p>	 <p><b>SPEECH THERAPY</b></p>	 <p><b>SPECIALIZED EDUCATION</b></p>
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**Family/Community**

 <p><b>HOME-BASED THERAPY</b></p>	 <p><b>DAILY PLAY</b></p>	 <p><b>HEALTHY DIET</b></p>
 <p><b>DO NOT MOCK OR STARE</b></p>	 <p><b>DO NOT ABUSE OR PHYSICALLY PUNISH</b></p>	 <p><b>JOIN/FORM A SUPPORT GROUP</b></p>

**Family/Community (For those with trouble swallowing)**

(AROUND 30% OF CHILDREN WITH CEREBRAL PALSY MAY HAVE THIS PROBLEM)

<p><b>FEED THEM SMALL AMOUNT AT A TIME</b></p>	 <p><b>MAKE SOFT FOOD</b></p>	 <p><b>FEED CHILD IN SEATED POSITION</b></p>
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### JEREMY

Jeremy has CP that limits his ability to move his arms and legs and speak clearly. When he was younger, his mother abandoned him because he had a disability.

Since he could not walk, his grandmother carried him everywhere on her back. Most people in Jeremy's community believed his CP was caused by a curse. They did not believe he would be successful in life. As a result, Jeremy lived in isolation from his community.

Fortunately, Jeremy's life was transformed when Kupenda/Kuhenza helped him to enroll in a school. There he received therapy services and an education. He also met many friends, including his best friend, Mohamed, who also has CP.

Jeremy is now a disability advocate in his community and works to protect other children with disabilities from abuse.

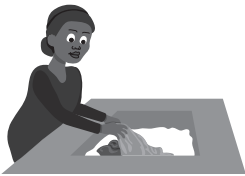
Thanks to therapy, he is also able to walk, though slightly imbalanced. Mohamed helps Jeremy to walk more steadily by letting him push his wheelchair.

Jeremy and Mohamed can always be found telling each other stories, though others may not understand their speech. They show the world the value of friendship and helping others.

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## INTERVENTIONS CONTINUED . . .

Family/Community (For those who are unable or have difficulty moving on their own)



**ENSURE THEY HAVE  
CLEAN CLOTHES**



**CHANGE THEIR  
POSITION OFTEN**



**PROVIDE PAMPERS  
(NAPKINS)**



**USE TOILET ADAPTATION**



**BATHE THEM AFTER  
SOILING THEMSELVES**



**PROVIDE ASSISTANCE  
DEVICES**

## NOTES

1. "Data and Statistics for Cerebral Palsy," Centers for Disease Control and Prevention, last modified December 31, 2020, <https://www.cdc.gov/ncbddd/cp/data.html>.
2. "11 Things to Know About Cerebral Palsy," Centers for Disease Control and Prevention, last modified March 1, 2021, <https://www.cdc.gov/ncbddd/cp/features/cerebral-palsy-11-things.html>.
3. "11 Things to Know About Cerebral Palsy," Centers for Disease Control and Prevention.
4. "What Is Cerebral Palsy?" Centers for Disease Control and Prevention, last modified September 2, 2021, <https://www.cdc.gov/ncbddd/cp/facts.html>.
5. "11 Things to Know About Cerebral Palsy," Centers for Disease Control and Prevention.
6. "Cerebral Palsy: Hope Through Research," NIH: National Institute of Neurological Disorders and Strokes, last modified September 29, 2021, <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Cerebral-Palsy-Hope-Through-Research>.
7. David Werner, *Disabled Village Children* (Berkeley: Hesperian Health Guides, 2018), 87-112.
8. "11 Things to Know About Cerebral Palsy," Centers for Disease Control and Prevention.
9. "Cerebral Palsy: Hope Through Research," NIH: National Institute of Neurological Disorders and Strokes.
10. "11 Things to Know About Cerebral Palsy," Centers for Disease Control and Prevention.
11. "What Is Cerebral Palsy?" Centers for Disease Control and Prevention.
12. "Cerebral Palsy: Hope Through Research," NIH: National Institute of Neurological Disorders and Strokes.
13. Werner, *Disabled Village Children*, 87-112.



# CLEFT LIP AND PALATE



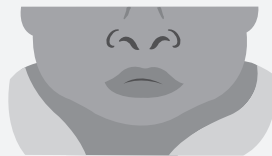
1 out of every 500 to 700 babies are born with cleft lip or palate.<sup>1,2</sup>

## DESCRIPTION <sup>3, 4, 5</sup>

Cleft (divided) lip and cleft palate are birth defects that occur when a baby's lip and/or top of the inside of the mouth (palate) don't completely form in a baby by the time he/she is born.

## SIGNS AND SYMPTOMS <sup>6, 7, 8</sup>

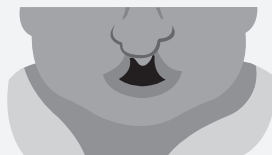
These are the different forms of cleft lip and palate. A child can have a normal looking lip but have a cleft palate or can have a cleft lip without a cleft palate.



NORMAL LIP



UNILATERAL CLEFT LIP AND PALATE INCOMPLETE



BILATERAL CLEFT LIP AND PALATE INCOMPLETE



UNILATERAL INCOMPLETE



NORMAL PALATE



CLEFT LIP



BILATERAL CLEFT LIP



CLEFT PALATE



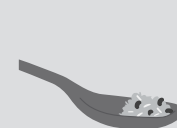
UNILATERAL CLEFT LIP AND PALATE



BILATERAL CLEFT LIP WITH FULL PALATE

## OTHER SIGNS AND SYMPTOMS <sup>9, 10, 11</sup>

There is wide variation in the number, type, and severity of signs and symptoms people experience.



DIFFICULTY SWALLOWING



DIFFICULTY BREASTFEEDING



CRYING SOUNDS LIKE IT IS COMING FROM NOSE



HEARING LOSS



TEETH PROBLEMS



## POSSIBLE CAUSES AND RISK FACTORS <sup>12, 13, 14</sup>



**FAMILY MEMBERS**  
with cleft lip or  
palate



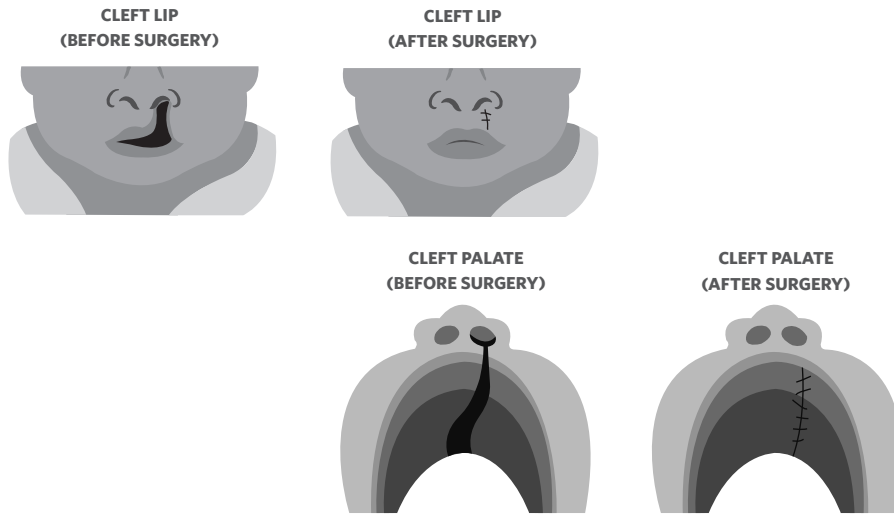
**PREGNANT MOTHER**  
SMOKING OR  
DRINKING ALCOHOL



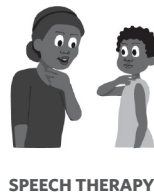
**MANY UNKNOWN**  
CAUSES

## INTERVENTIONS <sup>15, 16</sup>

### Professional Interventions: Surgery



### Additional Professional Interventions



### Family/Community



**DO NOT MOCK**  
OR STARE



**JOIN/FORM A**  
SUPPORT GROUP



**DO NOT ABUSE OR**  
PHYSICALLY PUNISH



## SOMAYA <sup>17</sup>

When Somaya was born with a cleft lip and palate, her father abandoned her. Her mother, Neny, however, never stopped praying for her daughter to be healed. Even when neighbors encouraged her to give Somaya away to an orphanage, Neny would not listen. "Somaya is a gift from God," she would say.

Somaya's lips made forming words nearly impossible. She had trouble eating and drinking. "She was always sick," Neny said. "She was always coughing." When it seemed all hope was lost, Somaya had surgery through an organization called Mercy Ships, where she met other families with cleft palates.

After Somaya's surgery, Neny couldn't stop smiling herself. "Now she is healthy!" she declared. "Now she can eat and drink normally. ... She says, 'Water, Mamma!'" As they prepared to return to their village, Neny couldn't wait to show her neighbors Somaya's sweet new smile. "They will be amazed to see her back with these lips," she said with a grin.

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## NOTES

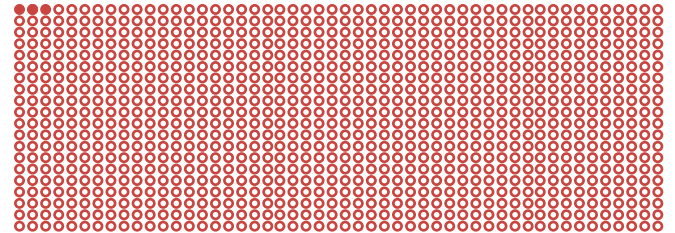
1. Alexis Caitlin Lanteri et al., "A Cross-Sectional Comparison of Cleft Lip Severity in 3 Regional Populations," *Eplasty* 12, no. 10 (February 3, 2012).  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3273313/#:~:text=While%20of%20children,every%20500%20to%20600%20births>.
2. David Werner, *Disabled Village Children* (Berkeley: Hesperian Health Guides, 2018), 121.
3. Werner, *Disabled Village Children*, 121.
4. "Facts About Cleft Lip and Palate," Centers for Disease Control and Prevention, last modified December 16, 2022, <https://www.cdc.gov/ncbddd/birthdefects/cleftlip.html>.
5. Neelam Phalke and Joshua J. Goldman, "Cleft Palate," *StatPearls* (September 26, 2022).  
<https://www.ncbi.nlm.nih.gov/books/NBK563128/>.
6. Werner, *Disabled Village Children*, 121.
7. "Facts About Cleft Lip and Palate," Centers for Disease Control and Prevention.
8. Phalke and Goldman, "Cleft Palate."
9. Werner, *Disabled Village Children*, 121.
10. "Facts About Cleft Lip and Palate," Centers for Disease Control and Prevention.
11. Phalke and Goldman, "Cleft Palate."
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13. "Cleft Lip and Palate," National Institute of Craniofacial Research, last modified January 2021, <https://www.nidcr.nih.gov/health-info/cleft-lip-palate>.
14. "Facts About Cleft Lip and Palate," Centers for Disease Control and Prevention.
15. Werner, *Disabled Village Children*, 121.
16. "Facts About Cleft Lip and Palate," Centers for Disease Control and Prevention.
17. Mercy Ships, "A Floating Hospital. A Second Chance," Stena Line, accessed July 3, 2023, <https://blog.stenaline.com/mercy-ships/a-floating-hospital-a-second-chance/>.



# CLUBFOOT

## DESCRIPTION <sup>2, 3, 4</sup>

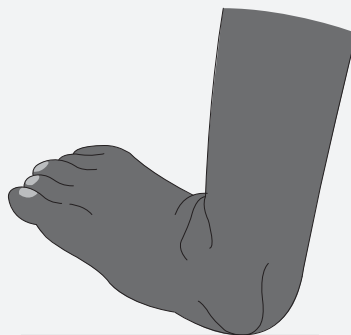
Clubfoot is a condition where one or both feet are in an uncommon position because tissues that connect muscles to bone in a baby's leg and foot are shorter than normal.



**3** out of every 1,000 children are born with clubfoot or feet.<sup>1</sup>

## SIGNS AND SYMPTOMS <sup>5, 6, 7</sup>

One or both feet may look like any of these.



## POSSIBLE CAUSES AND RISK FACTORS <sup>8, 9, 10</sup>



**FAMILY MEMBERS**  
who have clubfoot

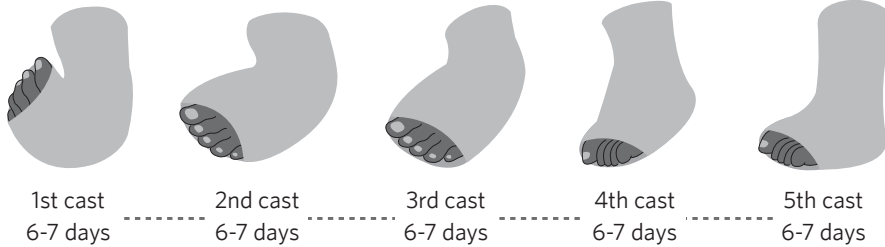


**UNKNOWN CAUSES**

## INTERVENTIONS <sup>11, 12, 13</sup>

### Professional Interventions: Casting

If caught early, medical professionals will often cast the impacted leg(s) to correct the clubfoot. This will vary depending on the severity.



*Note: Family and community members should keep the cast dry and clean. They should also check the foot/feet every day for any dark coloring or coldness in the toes to make sure the cast is not too tight. Take the child to the doctor if there is a fever, foul odor, or liquid coming from the cast or rashes/redness around the cast.*

### Additional Professional Interventions



**SURGERIES**



**REGULAR CHECKUPS**

### Family/Community



**DO NOT MOCK OR STARE**



**DO NOT ABUSE OR PHYSICALLY PUNISH**



**CANE OR STICK TO HELP THEM GET AROUND**



**JOIN/FORM A SUPPORT GROUP**



### JECINTA <sup>14</sup>

Seventeen years ago when Jecinta was born, her mother noticed that her feet looked unusual. As Jecinta continued to mature, her condition deteriorated. Her two feet twisted in the wrong direction. Her gait was also affected; she fell almost every time she walked. Due to a lack of information and finances, the family did not receive any assistance.

Doctors informed Jecinta that she had clubfoot. The good news was that it could be corrected! Surgeons performed a surgery to correct and align her feet. The operation helped Jecinta move around without much difficulty and alleviated her pain. It also significantly boosted her self-esteem, which will, in turn, make her more likely to pursue her dreams.

Jecinta has now fully recovered thanks to CURE Kenya!

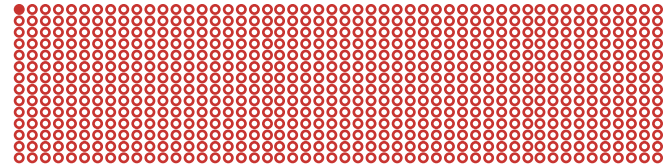
Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## NOTES

1. David Werner, *Disabled Village Children* (Berkeley: Hesperian Health Guides, 2018), 115.
2. Werner, *Disabled Village Children*, 115.
3. Alasdair Barrie and Matthew Varacallo, "Clubfoot," *StatPearls* (September 4, 2022).  
<https://www.ncbi.nlm.nih.gov/books/NBK551574/>.
4. "Birth Defects Surveillance Toolkit," Centers for Disease Control and Prevention, last modified November 27, 2020,  
<https://www.cdc.gov/ncbddd/birthdefects/surveillancemanual/chapters/chapter-4/chapter4.9a.html>.
5. Werner, *Disabled Village Children*, 115.
6. Barrie and Varacallo, "Clubfoot."
7. "Birth Defects Surveillance Toolkit," Centers for Disease Control and Prevention.
8. Werner, *Disabled Village Children*, 115.
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<https://orthoinfo.aaos.org/en/diseases--conditions/clubfoot/>.
11. Werner, *Disabled Village Children*, 116-117.
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13. "Clubfoot," OrthoInfo.
14. "New Hope for Jecinta," CURE International, last modified June 6, 2019,  
<https://cure.org/2019/06/new-hope-for-jecinta/>.



# DOWN SYNDROME



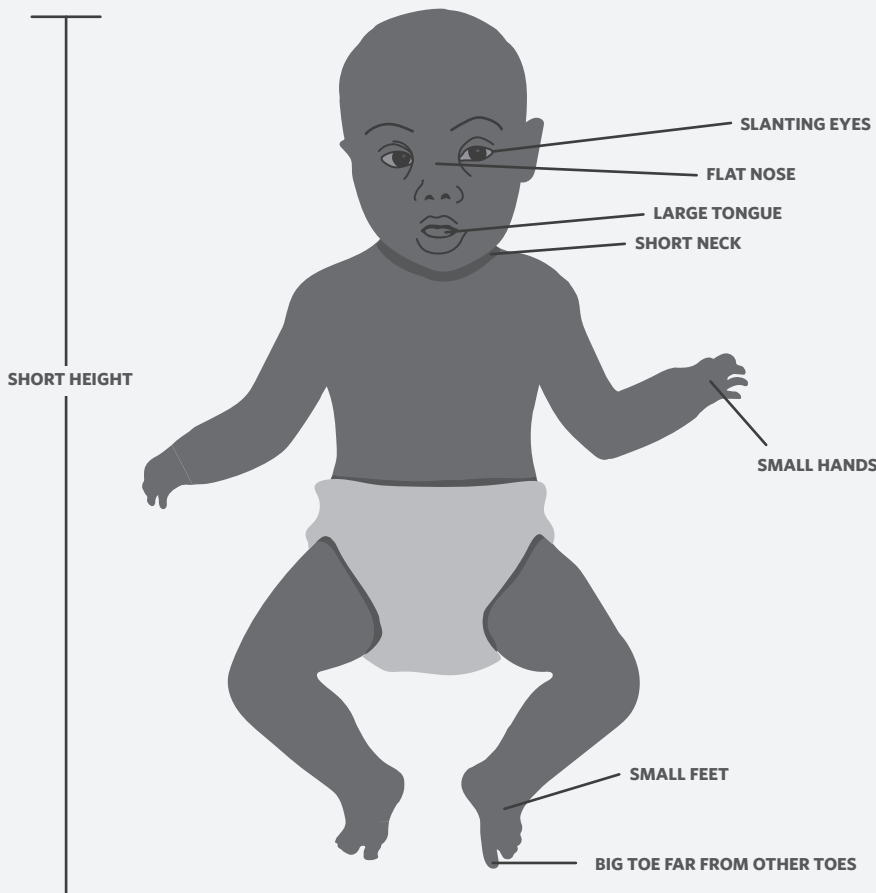
**1** out of every 700 babies is born with Down syndrome.<sup>1</sup>

## DESCRIPTION <sup>2, 3, 4</sup>

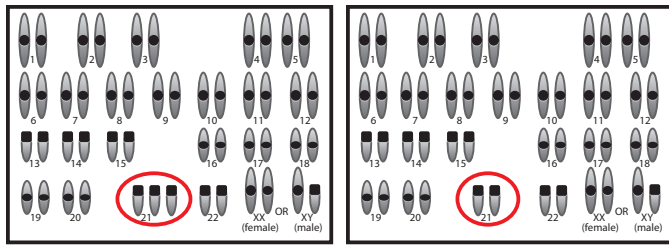
Down syndrome is the result of a specific extra chromosome (packet of information from the mother and father) that exists in a baby before birth. This condition results in lowered learning abilities and some physical differences and challenges.

## SIGNS AND SYMPTOMS <sup>5, 6, 7</sup>

There is wide variation in the number, type, and severity of signs and symptoms people experience.

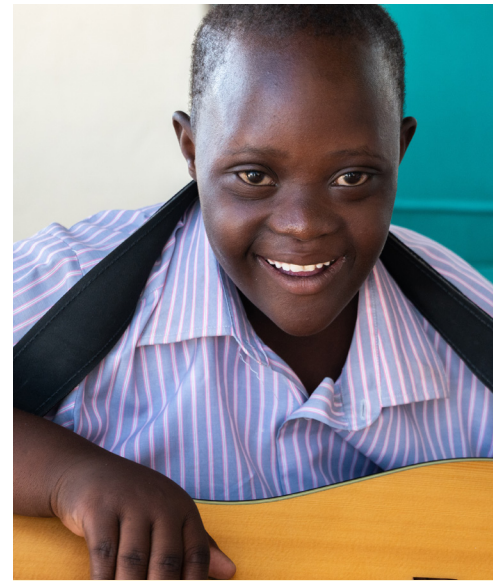


## POSSIBLE CAUSES AND RISK FACTORS <sup>8, 9, 10, 11</sup>



**EXTRA COPY OF THE 21<sup>ST</sup> CHROMOSOME**  
(packet of information from father or mother)

\*Note: 50% to 80% of babies with Down syndrome are born to women under 35 years old, but there is a higher percentage of Down syndrome births to people under 20 and over 35 years. <sup>12, 13, 14</sup>



## INTERVENTIONS <sup>15, 16, 17</sup>

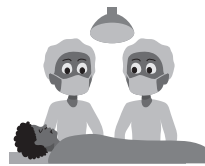
### Professional



**HEARING AIDS**



**MEDICATION FOR SYMPTOMS**



**SURGERIES**



**SPEECH THERAPY**

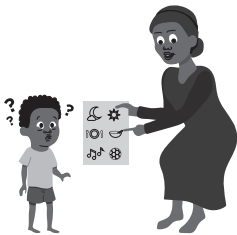


**PHYSICAL THERAPY**



**SPECIALIZED EDUCATION**

### Family/Community



**HAVE PATIENCE AS THEY LEARN THINGS SLOWER THAN OTHERS**



**DO NOT MOCK OR STARE**



**JOIN/FORM A SUPPORT GROUP**



**DO NOT ABUSE OR PHYSICALLY PUNISH**

**NOTE:** There is no medication or medical procedure that can remove Down syndrome, but these interventions can improve a person's quality of life.

## PETER

Peter is a 12-year-old with Down syndrome who lives on the coast of Kenya. Before he was born, his father, a pastor, thought disabilities were caused by witchcraft or were a punishment from God. Eventually, his father met other pastors who had learned that anyone can have a disability and that everyone is deserving of love. He also grew to recognize the importance of pastors sharing this message with others.

By the time Peter was born, his father accepted his son and taught his family and community to do the same. Today, Peter has a family that loves him and is part of a school that understands his needs. He enjoys music, telling jokes, and spending time with his friends. He is an example to others of what is possible when people with different types of abilities are given opportunities.

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## NOTES

1. "Data and Statistics on Down Syndrome," Centers for Disease Control and Prevention, last modified June 28, 2023, <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html#:~:text=Down%20syndrome%20continues%20to%20be,in%20every%20700%20babies%20born.>
2. "Facts about Down Syndrome," Centers for Disease Control and Prevention, last modified June 28, 2023, <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html>.
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4. "About Down Syndrome," National Institutes of Health, last modified June 20, 2018, <https://www.nih.gov/include-project/about-down-syndrome#:~:text=Down%20syndrome%20is%20a%20condition,a%20variety%20of%20birth%20defects.>
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# DWARFISM



Up to 1 out of every 15,000 children have some form of dwarfism. <sup>1</sup> One open dot = 100

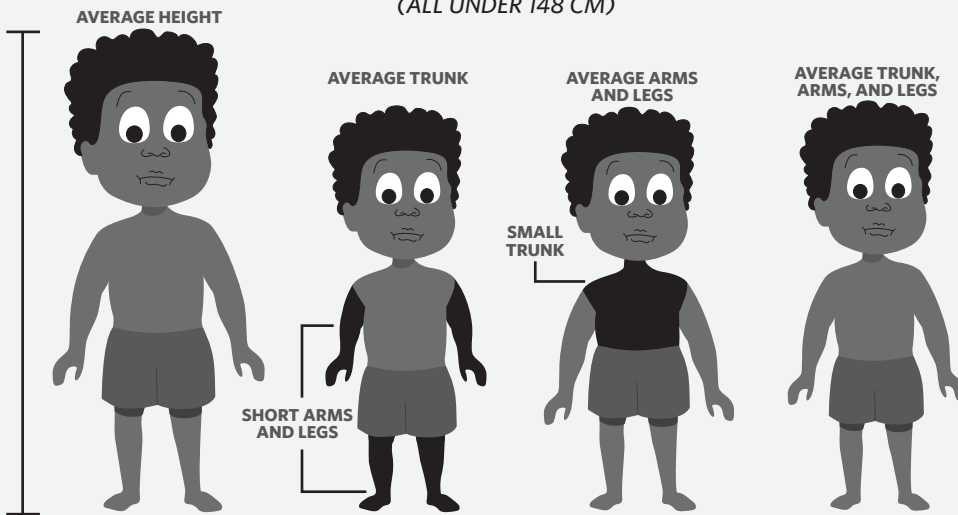
## DESCRIPTION <sup>2, 3, 4</sup>

There are about 400 different conditions resulting in dwarfism. All conditions are characterized by a person reaching an adult height of less than 148 cm (4 ft 10 in).

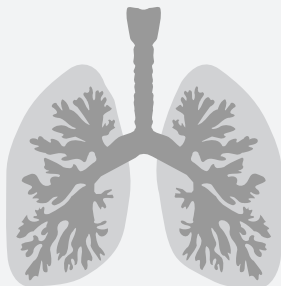
## SIGNS AND SYMPTOMS <sup>5, 6, 7, 8</sup>

*(There is wide variation in the number, type, and severity of signs and symptoms people experience.)*

BELOW ARE THREE OF THE MAIN CATEGORIES OF DWARFISM (ALL UNDER 148 CM)

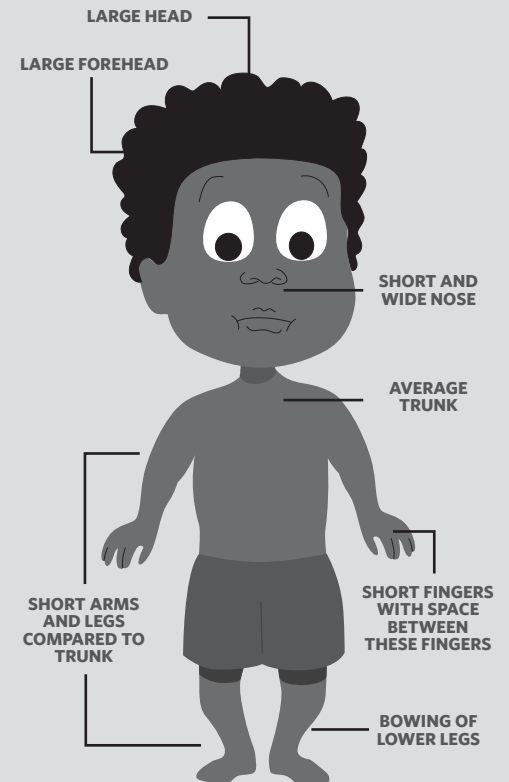


SOME HAVE BREATHING PROBLEMS, BACK PROBLEMS, OR HYDROCEPHALUS (FLUID AROUND THE BRAIN).



THE MOST COMMON TYPE OF DWARFISM IS CALLED ACHONDROPLASIA AND ACCOUNTS FOR 70% OF PEOPLE WITH DWARFISM. <sup>9</sup>

### ACHONDROPLASIA FEATURES



## POSSIBLE CAUSES AND RISK FACTORS <sup>10, 11</sup>



### MALNUTRITION

Pregnant mother or child not getting enough or the right types of food



### FAMILY MEMBERS

who have dwarfism

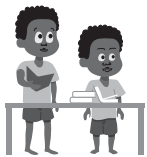
## INTERVENTIONS <sup>12, 13</sup>

### Professional



**SURGERIES (FOR BACK ISSUES, SEVERE BREATHING ISSUES, OR HYDROCEPHALUS)**

### Family/Community



**ENROLL IN MAINSTREAM SCHOOL**



**DO NOT MOCK OR STARE**



**DO NOT ABUSE OR PHYSICALLY PUNISH**



**ENSURE PEOPLE WITH DWARFISM CAN REACH THINGS LIKE EVERYONE ELSE**



**JOIN/FORM A SUPPORT GROUP**



### LAURITTA ONYE <sup>14, 15</sup>

Lauritta Onye is a Paralympian athlete with achondroplasia from Nigeria. With a history in acting, her life changed course when she pursued sports in 2007.

Competing in throwing events, she won silver at the 2011 All Africa Games. In 2015, she went on to set a new world record, earn the world title, and podium in the Rio Paralympic Games. She also became the first in her class to throw 8.40m to win Paralympic gold.

According to Onye, her disability does not prevent her from achieving. "I have determination in this; power and strength and determination in me. I can see the distance that I throw increase—look at what I threw in 2007 compared to 2011 and 2015. The more I train the more the distance that I throw is growing. I can't give up, I'm still winning," she said. Onye concluded "That's what I want - for me to be the champion. That's what pushes me, what inspires me. Determination keeps me going."

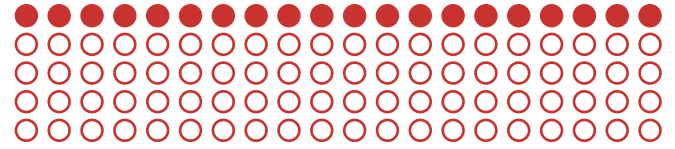
Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## NOTES

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3. Megha Jain and Ahmed Y. Saber, "Dwarfism," *StatPearls* (October 10, 2022). <https://www.ncbi.nlm.nih.gov/books/NBK563282/>.
4. "Dwarfism," Mayo Clinic, last modified August 17, 2018, <https://www.mayoclinic.org/diseases-conditions/dwarfism/symptoms-causes/syc-20371969>.
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# DYSLEXIA



## DESCRIPTION <sup>2, 3, 4, 5</sup>

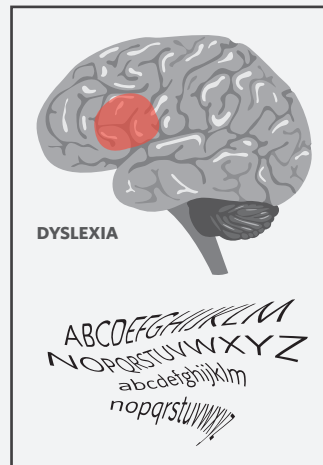
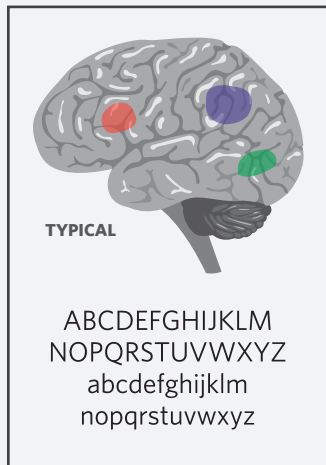
Difficulty reading, spelling, or understanding written words not connected to intelligence or lack of education

Up to **18** out of every 100 people have dyslexia.<sup>1</sup>

## SIGNS AND SYMPTOMS <sup>6, 7, 8</sup>

(There is wide variation in the number, type, and severity of signs and symptoms people experience.)

The red area is the part of the brain that connects sounds to letters. It is larger in dyslexic brains because they compensate for the less active areas (blue and green) responsible for memorizing words and learning new ones.



## OTHER SIGNS AND SYMPTOMS

WITHOUT INTERVENTION INDIVIDUALS WITH DYSLEXIA COULD EXPERIENCE



WORRY



SADNESS



ANGER



DIFFICULTY READING OR DOING MATH COMPARED TO OTHERS THEIR AGE



AVOIDS READING



CHALLENGES WITH SPEECH



MEMORY PROBLEMS




TAKING LONGER THAN OTHERS TO FINISH SCHOOL WORK OR CHORES




CREATIVE THINKING

## POSSIBLE CAUSES AND RISK FACTORS <sup>9, 10, 11</sup>



**FAMILY MEMBERS**  
with dyslexia



**BRAIN STRUCTURE**  
difference in area  
connected to reading

## INTERVENTIONS <sup>12, 13, 14</sup>

### Family/Community



**DO NOT ABUSE  
OR PHYSICALLY PUNISH**



**SPECIALIZED  
EDUCATION**



**JOIN/FORM A  
SUPPORT GROUP**



**REWARD GOOD  
BEHAVIOR**



**DO NOT MOCK OR STARE**



## WHOOPI <sup>15</sup>

In her youth, Whoopi Goldberg struggled to learn and was labeled “dumb” and “lazy.” As a result, she dropped out of school and became involved in drugs..

When Goldberg realized she had dyslexia, it was lifechanging. Her mother told her that she wasn’t stupid and could be and do anything she wanted. She herself realized she couldn’t be stupid because, as she says, “If you read to me, I could tell you everything you read.” Her mother’s attitude, coupled with her own determination, took her off drugs and drove her to succeed.

Today Goldberg has an amazing career as an actress, comedian, television host, and author. Ultimately, she says thinking differently has helped her succeed.

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## NOTES

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3. "Dyslexia," National Institute of Neurological Disorders and Stroke, last modified January 20, 2023, <https://www.ninds.nih.gov/health-information/disorders/dyslexia>.
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8. "Definition of Dyslexia," International Dyslexia Association.
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13. "Dyslexia," National Institute of Neurological Disorders and Stroke.
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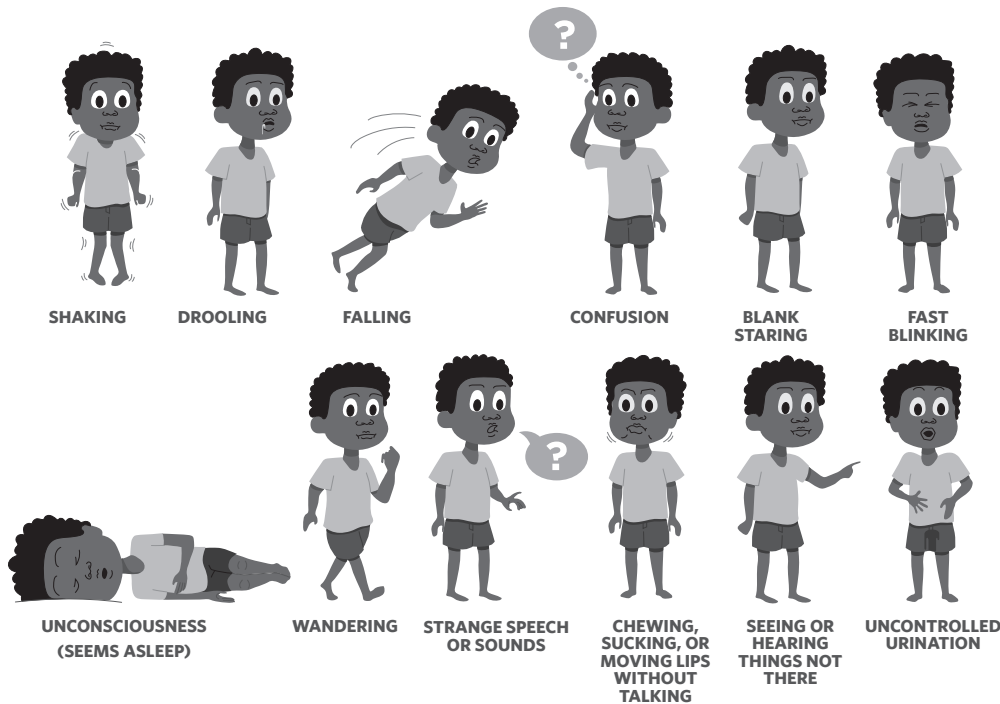
# EPILEPSY

## DESCRIPTION <sup>2,3</sup>

Epilepsy is a disorder where there is a sudden change in normal brain activity which causes the person to have several seizures or “fits” over a long period of time.

## SIGNS AND SYMPTOMS <sup>4,5,6,7,8,9</sup>

Someone who is having a seizure may show one or more of the following symptoms before or during a seizure. Others may not show any signs before their seizure.



More **1** out of every 100 than people have epilepsy.<sup>1</sup>

## TRIGGERS FOR A SEIZURE





Avoiding these triggers may reduce the number of seizures a person with epilepsy experiences.



## SEIZURES MAY

- Last for seconds or up to several minutes
- Lead to death or brain damage if they last longer than 30 minutes
- Not be remembered by the person who experiences them
- Cause memory loss overall, depending on the number and severity of the seizures
- Occur multiple times in a day or only once in a year (sometimes only every few years)
- Happen while the person is sleeping
- Stop when a child becomes an adult (true for half of people with epilepsy)

## POSSIBLE CAUSES AND RISK FACTORS <sup>10, 11, 12, 13</sup>

 <b>INFECTION</b> from diseases that damage the brain	 <b>INJURY</b> to the head	 <b>DISORDERS</b> or disabilities that impact the brain	 <b>OXYGEN DEPRIVATION</b> to the brain	 <b>FAMILY MEMBERS</b> with epilepsy
--	---	--	--	--

**NOTE:** Epilepsy has biological causes that can be treated with medicine and is not the result of witchcraft or demons.

## INTERVENTIONS <sup>14, 15, 16</sup>

Anti-seizure medication is the most effective treatment for people with epilepsy. If taken as directed by the doctor, medications may completely stop seizures for some people or reduce the frequency and severity of the seizures for others. There are also different kinds of medication. If one doesn't work, the individual should go back to the doctor to see if a different kind of medication may work better. Some people will need medicine their whole lives, while others may not need it as long.

### Professional



MEDICATIONS



HELMET

### Family/Community



HEALTHY DIET



TAKE MEDICINE AS DIRECTED



HAVE ENOUGH MEDICINE



ENSURE FAMILY IS TAKING THE CHILD FOR REGULAR DOCTOR VISITS



JOIN/FORM A SUPPORT GROUP



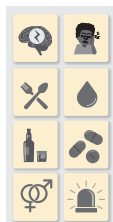
DO NOT ABUSE OR PHYSICALLY PUNISH



DO NOT MOCK OR STARE



HELP THE PERSON WHEN HE/SHE HAS A SEIZURE (SEE NEXT PAGE)



AVOID TRIGGERS (SEE PREVIOUS PAGE)



## HANIFA

When Hanifa was three years old, she developed seizures due to a high fever from an unknown infection. Even after her fever went away, the seizures continued for years. Sometimes there were as many as seven seizures in a day.

Her family did not understand why she continued to have these attacks. Many people in their community believed that the symptoms were the result of an evil spirit and recommended she consult with local faith healers.


When Hanifa was put in touch with Kuhenza/Kupenda, however, local staff helped the family understand the biological cause of her disability and connected her to an epilepsy specialist who prescribed her appropriate medication. Today Hanifa has just a few mild seizures in a year. She is able to attend school and learn like anyone else.

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)




## Family/Community (During a seizure)

As soon as a person becomes aware that someone is going to have a seizure or is having a seizure, he or she should follow these steps.




**MOVE ANY OBJECTS AWAY FROM THE PERSON**

**DO NOT PUT ANYTHING IN THE PERSON'S MOUTH**




**DO NOT HOLD THE PERSON DOWN**


**LAY THE PERSON ON HIS OR HER SIDE TO PREVENT CHOKING**



**RECORD HOW LONG THE SEIZURE LASTS AND HOW LONG THE PERSON IS UNABLE TO RESPOND**



**GIVE THE PERSON TIME**  
to relax after the seizure is over, as the person will likely be tired and confused.



**CALL A MEDICAL PROFESSIONAL**  
if the person is unable to respond after 15 minutes. Tell him or her how long the seizure or unresponsiveness lasted.

## NOTES

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2. "Epilepsy: About Epilepsy," Centers for Disease Control and Prevention, last modified September 30, 2020, <https://www.cdc.gov/epilepsy/about/>.
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16. Werner, *Disabled Village Children*, 233-242.



# FETAL ALCOHOL SYNDROME DISORDERS (FASD)



**1-5** out of every 100 children may have a fetal alcohol syndrome disorder in western countries, but research on this is limited in low-income countries.<sup>1</sup>

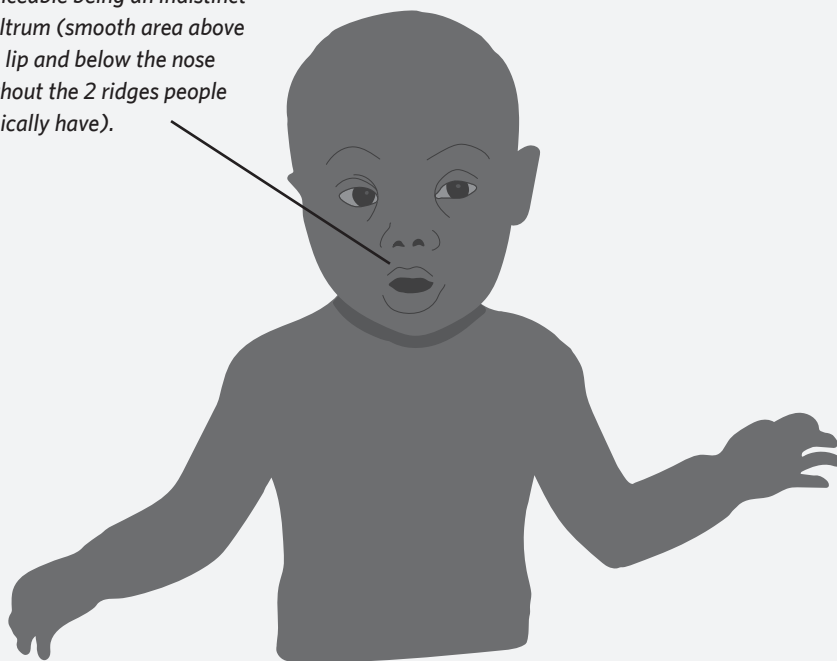
## DESCRIPTION <sup>2, 3</sup>

A group of conditions that can occur in a person whose mother drank alcohol during pregnancy which may cause the child to have problems physically, behaviorally, and intellectually.

## SIGNS AND SYMPTOMS <sup>4, 5, 6</sup>

*(There is wide variation in the type and severity of symptoms people experience.)*

*Their faces have differences compared to children without FASD (photo), with the most noticeable being an indistinct philtrum (smooth area above the lip and below the nose without the 2 ridges people typically have).*



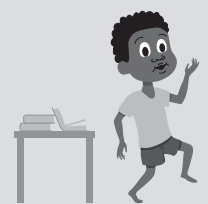
LEARNING CHALLENGES



SPEECH CHALLENGES



RASH DECISION MAKING



MOVE AROUND A LOT



LOW BIRTH WEIGHT



PROBLEMS WITH HEART, KIDNEYS, AND VISION

## POSSIBLE CAUSES AND RISK FACTORS <sup>7, 8, 9, 10</sup>



**EXPOSURE**  
to alcohol during  
pregnancy

## INTERVENTIONS <sup>11, 12</sup>

### Professional



**MEDICATIONS**



**SPECIALIZED COUNSELING**



**SPECIALIZED  
EDUCATION**

### Family/ Community



**JOIN/FORM A  
SUPPORT GROUP**



**DO NOT ABUSE OR  
PHYSICALLY PUNISH**



**REWARD GOOD  
BEHAVIOR**



**DO NOT MOCK  
OR STARE**



### **ANDREW** <sup>13, 14, 15</sup>

Andrew Peterson was born after months in the womb soaking up the alcohol his mother drank.

He was found alone in his mother's home at three weeks old. Andrew would grow into a 5-year-old who didn't run, didn't laugh easily, and didn't understand the world around him. In addition, kids made fun of him in school.

Eventually, Peterson grew to be an athlete—an athlete that won 50 gold medals from state competitions and 4 golds from national competition.

Today he talks to others about having Fetal Alcohol Syndrome, his years of physical therapy, and about how he joined the cross-country team and won gold medals. But the greatest honor, he tells the students, is to have people's respect.

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## NOTES

1. "Data & Statistics on FASDs," Centers for Disease Control and Prevention, last modified January 18, 2023, <https://www.cdc.gov/ncbddd/fasd/data.html>.
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# HEARING LOSS OR DEAFNESS



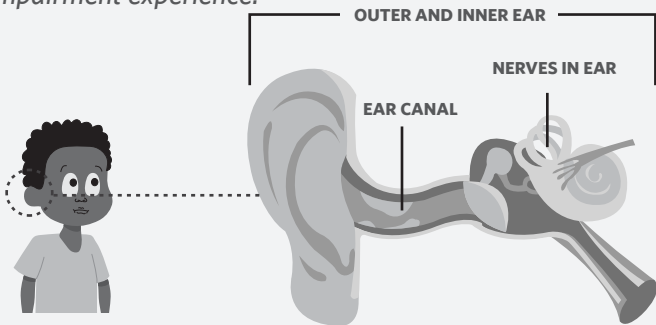
5 out of every 100 people have significant hearing loss around the world. 60% of cases in children could be prevented.<sup>1</sup>

## DESCRIPTION<sup>2,3</sup>

Inability to hear the same level or type of sound as people without hearing loss, typically impacting the ability to verbally communicate.

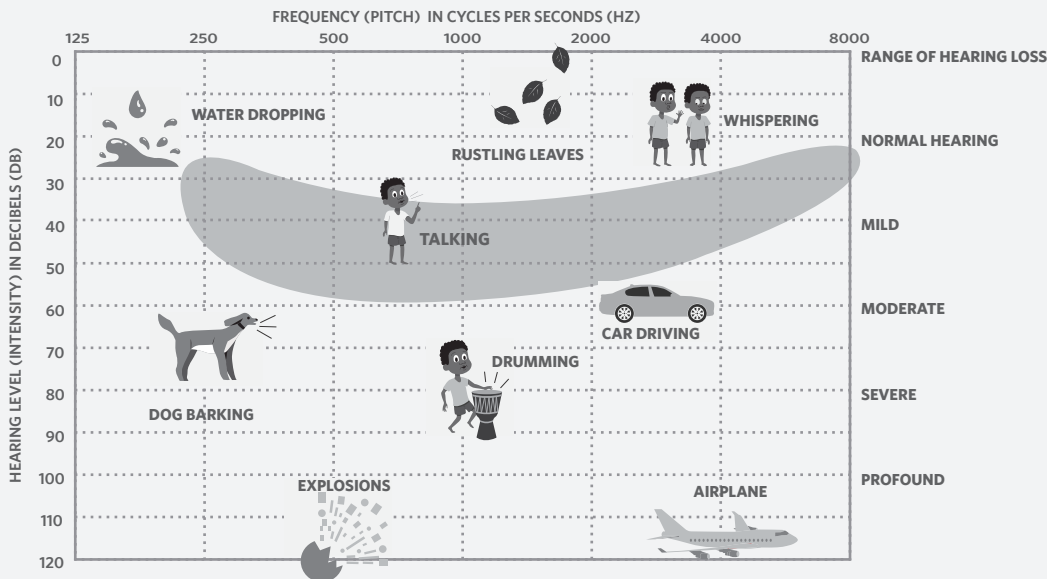
## SIGNS AND SYMPTOMS<sup>4,5,6,7,8</sup>

There is variation in the types and levels of sounds people with hearing impairment experience.



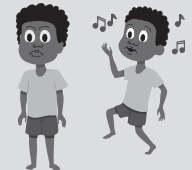
There are three types of hearing loss

1. Damage or blockage (such as ear wax) to the ear canal, which can often be repaired
2. Damage to the nerves in the ear, which is the most common type of hearing loss and typically cannot be repaired
3. Damage to the nerves and the ear canal

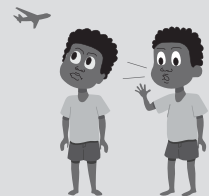


This chart shows the sounds people can hear with different levels of hearing loss. This is the typical way to classify hearing loss, but there are some people who only hear high sounds (like birds) but not low sounds (like trucks).

## OTHER SIGNS AND SYMPTOMS



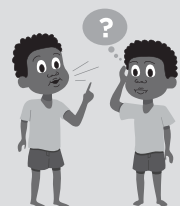
DOES NOT TURN TO THE SOURCE OF A SOUND OR REACT TO LOUD NOISES



RESPONDS TO SOME TYPES OF SOUNDS BUT NOT OTHERS







CHALLENGE WITH LANGUAGE OR SPEECH



TROUBLE UNDERSTANDING PEOPLE TALKING



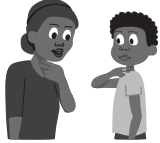

## POSSIBLE CAUSES AND RISK FACTORS <sup>9, 10, 11</sup>

			
<p><b>FAMILY MEMBERS</b> with hearing loss</p>	<p><b>INJURY</b> to the brain from accidents</p>	<p><b>PROBLEMS</b> during birth</p>	<p><b>INFECTION</b> in child or mother (before birth)</p>

## INTERVENTIONS <sup>12, 13, 14</sup>

Interventions may be different depending on the severity of hearing loss.

### Professional

 <p><b>HEARING AIDS</b></p>	 <p><b>VISIT A HEARING SPECIALIST</b></p>	 <p><b>SPEECH THERAPY</b></p>	 <p><b>ENROLL IN SIGN LANGUAGE CLASS</b></p>
--	--	--	---

### Family/Community

 <p><b>FACE PERSON WHEN SPEAKING TO HIM/HER</b></p>	 <p><b>SPEAK CLEARLY WITHOUT BACKGROUND NOISE</b></p>	 <p><b>FAMILY AND COMMUNITY SHOULD LEARN SIGN LANGUAGE</b></p>
 <p><b>JOIN/FORM A SUPPORT GROUP</b></p>	 <p><b>DO NOT MOCK OR STARE</b></p>	 <p><b>DO NOT ABUSE OR PHYSICALLY PUNISH</b></p>



## HASSAN

Hassan is a 23-year-old young man with little hearing from the time he was a baby. His family did not believe someone who was deaf could be educated and kept him at home to tend to the goats. The director of Kuhenza visited Hassan's family many times to convince them that he was able to go to school.

Eventually, Hassan attended classes and thrived. Even though he started school at an older age than his peers, he learned sign language and other subjects quickly. He is now doing well in his second year of high school and continues to win running races and soccer at the national level.

One of Hassan's most impressive accomplishments was reaching the top of Mount Kilimanjaro and starring in a documentary about it. The boy who was told he had limited options for his future is now a local hero.

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## NOTES

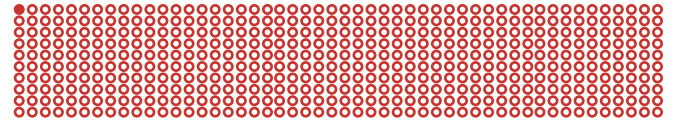
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2. "Deafness and Hearing Loss," World Health Organization, accessed February 15, 2023, [https://www.who.int/health-topics/hearing-loss#tab=tab\\_1](https://www.who.int/health-topics/hearing-loss#tab=tab_1).
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# HYDROCEPHALUS

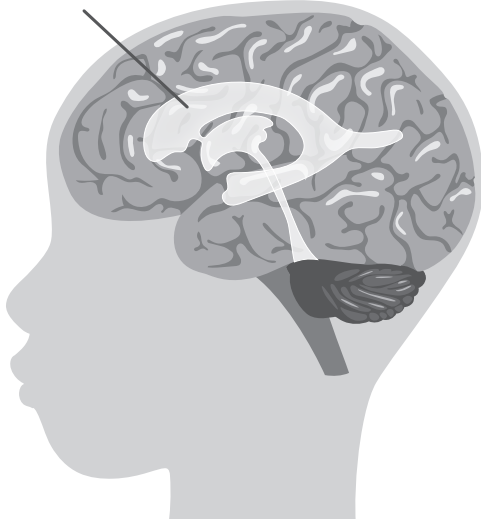
## DESCRIPTION <sup>3, 4, 5</sup>

Extra fluid on the brain, typically in an infant, resulting in a larger-than-average head size. <sup>3,4,5</sup>



**1** out of every 500 children develop hydrocephalus before the age of 2, though it is more common in low-income countries. <sup>1,2</sup>

NORMAL SPACE



ENLARGED SPACE



These two graphics depict the increasing buildup of fluid in spaces of the brain as well as the subsequent head size of a child with hydrocephalus, compared to a child without hydrocephalus.

## SIGNS AND SYMPTOMS <sup>6, 7, 8, 9, 10</sup>

People with hydrocephalus have several symptoms that differ in severity from one person to another.



HEADACHE



DIZZINESS



STOMACHACHE



VOMITING



DIFFICULTY SEEING



SLEEPINESS



EYES ALWAYS LOOKING DOWN



LEARNING CHALLENGES



SEIZURES (FITS)









INABILITY OR DIFFICULTY WALKING



OTHER DISABILITIES LIKE SPINA BIFIDA



## POSSIBLE CAUSES AND RISK FACTORS <sup>11, 12, 13</sup>

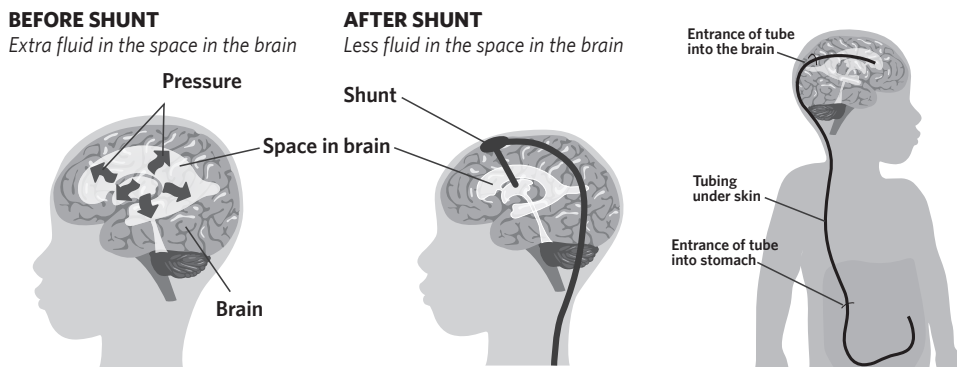
					
<b>INFECTION</b> from diseases that damage the brain	<b>SPINA BIFIDA</b>	<b>TUMORS</b> in the brain	<b>PREMATURE</b> child is born too early	<b>PROBLEMS</b> during birth	<b>INJURY</b> to the brain from accidents

## INTERVENTIONS <sup>14, 15, 16</sup>






### Professional Interventions: Inserting a shunt

A doctor trained in hydrocephalus may decide it is best to insert a tube (shunt) in the brain. This tube will drain the fluid from the brain to the stomach, heart, or lining of the lungs and be absorbed by the body.


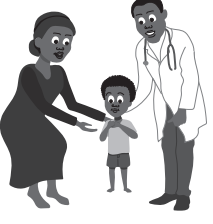

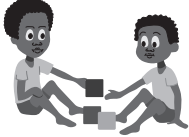
\*This intervention may be necessary to prevent death or increased damage to the brain.



### Additional Professional Interventions

				
<b>MEDICATION TO HELP WITH THE PAIN</b>	<b>PHYSICAL THERAPY</b>	<b>SPEECH THERAPY</b>	<b>SPECIALIZED EDUCATION</b>	<b>REGULAR CHECKUPS</b>

### Family/Community

			
<b>KEEP SHUNT SITE CLEAN</b>	<b>ENSURE THE FAMILY IS TAKING THE CHILD FOR REGULAR DOCTOR VISITS AFTER SHUNT IS PUT IN</b>	<b>HOME-BASED THERAPY</b>	<b>DAILY PLAY</b>



## JUSTINE

Justine developed hydrocephalus after coming down with an infection at 6 months old. The pain caused him to cry most of the time. His parents thought he would surely die, so they took him to local healers.

The condition continued to get worse until Kuhenza/Kupenda referred him to Bethany Kids Kijabe Hospital. Doctors there inserted a shunt into his head to drain excess fluid from around his brain.

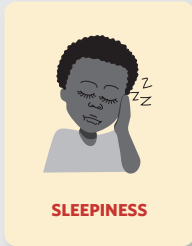
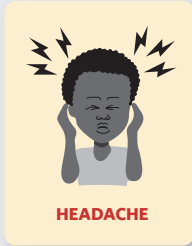
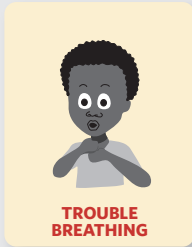
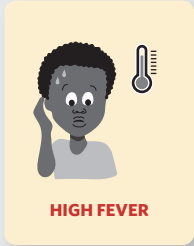
Eventually, Justine was able to walk on his own at 4 years old. Although he was delayed in his early development, physical therapy and the support of his family helped him significantly.

Today Justine is 9 years old and enrolled in a mainstream school in his community, like any other child his age. He has many friends and loves his life!

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## SIGNS OF INFECTION

Watch for signs of infection and visit a doctor if any of these symptoms arise.



## INTERVENTIONS CONTINUED . . .

### Family/Community



HEALTHY DIET



JOIN/Form A SUPPORT GROUP



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH

### Family/Community (For those who are unable or have difficulty moving on their own)



CHANGE THEIR POSITION OFTEN



ENSURE THEY HAVE CLEAN CLOTHES



BATHE THEM AFTER SOILING THEMSELVES



USE TOILET ADAPTATION



PROVIDE PAMPERS (NAPKINS)



PROVIDE ASSISTANCE DEVICES

### NOTES

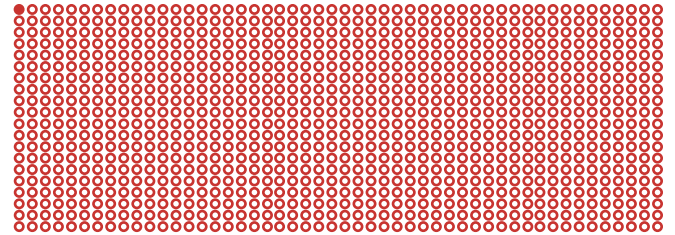
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- "Hydrocephalus Fact Sheet," NIH: National Institute of Neurological Disorders and Stroke.
- David Werner, *Disabled Village Children* (Berkeley: Hesperian Health Guides, 2018), 168-169.
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- "Hydrocephalus Fact Sheet," NIH: National Institute of Neurological Disorders and Stroke.
- "Hydrocephalus Information Page," NIH: National Institute of Neurological Disorders and Stroke.
- Werner, *Disabled Village Children*, 168-169.



# LIMB LOSS OR REDUCTION

## DESCRIPTION <sup>2,3</sup>

Characteristics of limb loss or reduction include limbs that are either partially or entirely missing or deformed.

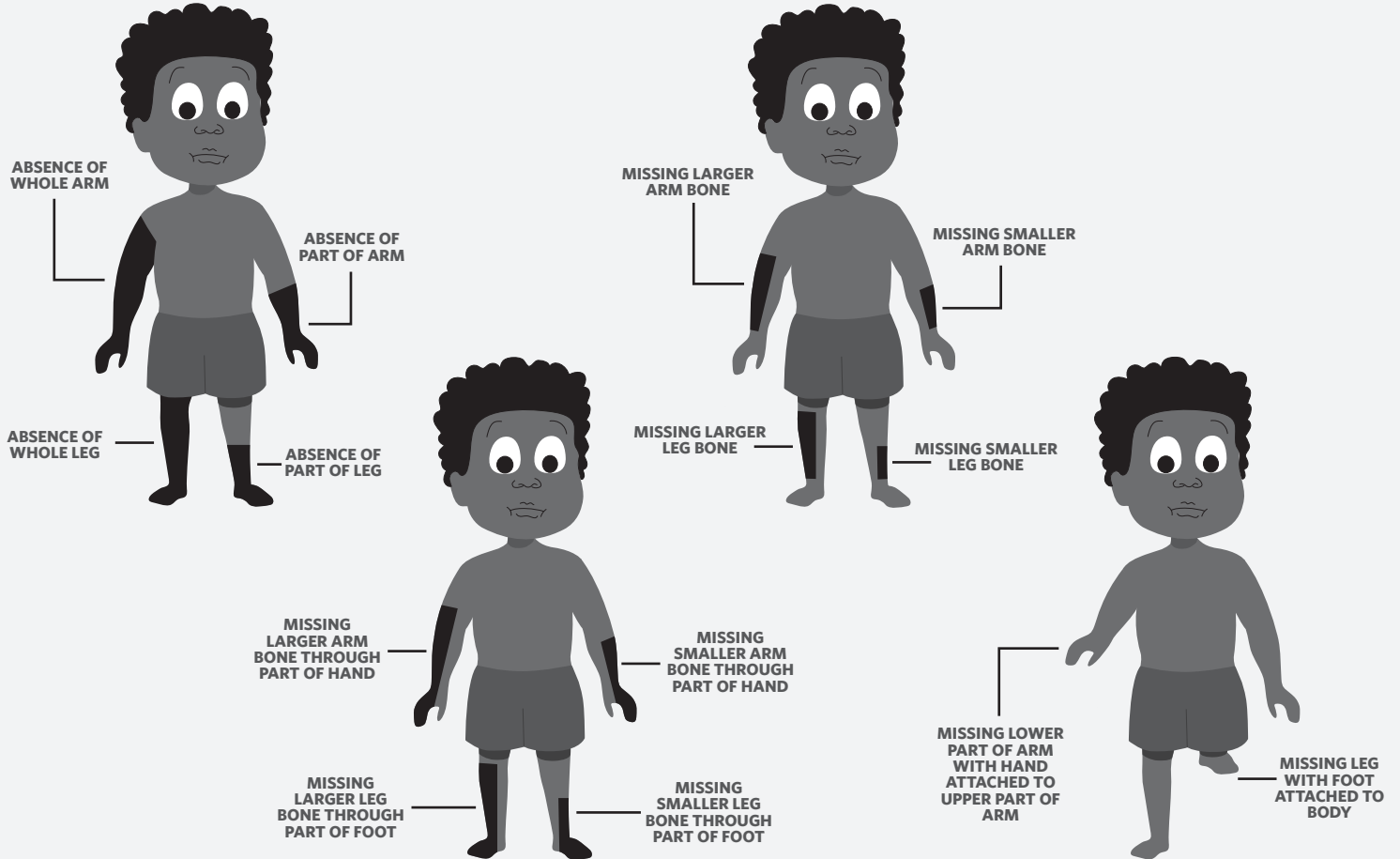


Up **1** out of every 1,900 children are born with one or more limbs missing or different from others. (This does not include those with limb differences acquired after birth.)<sup>1</sup>

## SIGNS AND SYMPTOMS <sup>4,5,6</sup>

(People may be affected in one or multiple areas of the arms, legs, hands, or feet.)

COMMON KINDS OF MISSING OR DIFFERENTLY FORMED ARMS AND LEGS:



## POSSIBLE CAUSES AND RISK FACTORS <sup>7</sup>



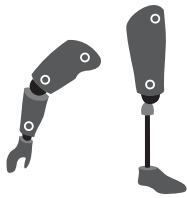
**FAMILY MEMBERS**  
who have limb loss  
or reduction



**MANY UNKNOWN**  
**CAUSES**

## INTERVENTIONS <sup>8,9</sup>

### Professional



**ARTIFICIAL LIMBS**  
(SOME CHILDREN MAY PREFER  
NOT TO USE THEM)



**PROVIDE ASSISTANCE**  
**DEVICES**



**PHYSICAL**  
**THERAPY**

### Family/Community



**ENROLL IN**  
**MAINSTREAM**  
**SCHOOL**



**JOIN/FORM A**  
**SUPPORT GROUP**



**DO NOT MOCK**  
**OR STARE**



**DO NOT ABUSE OR**  
**PHYSICALLY PUNISH**



### JOYCE

When Joyce was born, her mother wondered what she had done wrong to have a child born without a hand.

She questioned whether God was punishing her for something. Her parents didn't know what to do or where to turn for help. A child with a disability was viewed as a source of shame and a disgrace to the family. Eventually, the midwife who delivered Joyce brought the family to the Kupenda Center. There she met the Kenya director and a pastor as well as the U.S. Director, Cynthia, who was also born without a hand. Cynthia demonstrated that, although she did not have a hand, she was not limited academically, physically, or socially. In fact, Cynthia's condition inspired her to create Kupenda, an organization that helps thousands of children with disabilities. After many interactions with Cynthia, Joyce is now fully included in her village like any other child. Today she can do activities like other girls in her community, such as carrying water on her head and attending mainstream school where she is at the top of her class. Joyce continues to thrive and has gone on to influence people around the world as a featured child in the book, "An Unlikely Gift," a story about Kupenda's formation.

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

**NOTES**

1. "Facts about Upper and Lower Limb Reduction Defects," Centers for Disease Control and Prevention, last modified June 28, 2023, <https://www.cdc.gov/ncbddd/birthdefects/ul-limbreductiondefects.html#:~:text=Researchers%20estimate%20that%20about%201,and%20lower%20limb%20reduction%20defects.>
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3. David Werner, *Disabled Village Children* (Berkeley: Hesperian Health Guides, 2018), 227.
4. "Facts about Upper and Lower Limb Reduction Defects," Centers for Disease Control and Prevention.
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# MAJOR DEPRESSION



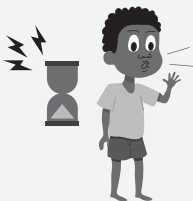
7 out of every 100 people experience major depression at some point in their life.<sup>1</sup>

## DESCRIPTION <sup>2,3,4,5</sup>

A person with this disorder has feelings of sadness that get in the way of eating, sleeping, working, or doing normal daily activities on most days for at least two weeks at a time.

## SIGNS AND SYMPTOMS <sup>6,7,8,9</sup>

(There is a wide variation in the type and severity of symptoms people experience, but people with major depression have 5 or more of the following symptoms.)



**SLOW SPEECH AND MOVEMENT**



**APPETITE AND WEIGHT CHANGES**



**NO LONGER INTERESTED IN ACTIVITIES THEY ONCE ENJOYED**



**TROUBLE CONCENTRATING AND MAKING DECISIONS**



**PHYSICAL SYMPTOMS (SUCH AS MUSCLE PAIN, HEADACHES, OR STOMACH PROBLEMS)**



**THOUGHTS OF DEATH OR SUICIDE**



**SLEEPING TOO LITTLE OR TOO MUCH**



**FEELING SAD**



**EASILY ANGERED OR ANNOYED (IN CHILDREN THIS MAY BE MORE PRESENT THAN SADNESS)**



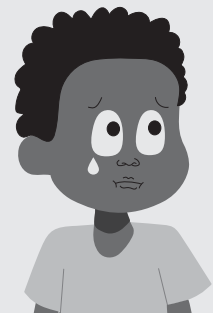
**TIRED**




**FEELING NOT GOOD ENOUGH OR GUILTY WITHOUT REASON**

## STIGMA OF DEPRESSION <sup>10</sup>


There are many negative cultural views associated with depression. These attitudes may make someone feel embarrassed or ashamed to be who they are and/or to seek help. Depression affects people regardless of their age, appearance, or success in life. It is a disease that is not always possible for a person to control. People with depression should receive help and compassion just like people with any other illness.




## POSSIBLE CAUSES AND RISK FACTORS <sup>11, 12</sup>




**BRAIN CHEMISTRY**




**FAMILY MEMBERS**  
with depression



**MAJOR LIFE CHANGES**  
(new job or home)



**LOSS OR TRAUMA**



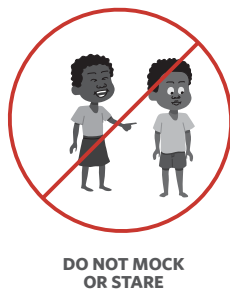
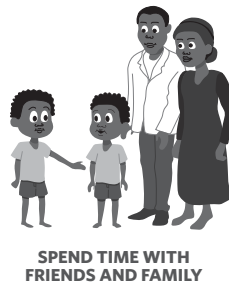
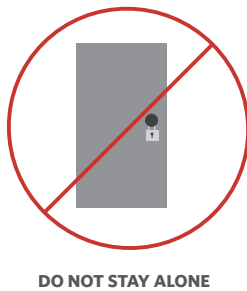
**ILLNESSES OR MEDICATIONS**  
that affect the brain

## INTERVENTIONS <sup>13, 14</sup>

### Professional



### Family/Community



### KERRY <sup>15, 16</sup>

Kerry Washington, an American actress, hasn't been shy about her past battle with depression.

In an interview with Essence magazine, she disclosed that much of her college experience revolved around a depression that including an "abusive relationship with food and exercise." "I used food as a way to cope," she said. "It was my best friend." It was only when a dance teacher intervened that Washington began what would become years of therapy and was finally able to end her routine of "eat, pass out, exercise for hours, feel guilty." More recently, Washington has worked closely with figures like Michelle Obama and Sarah Jessica Parker to call attention to the issue of depression, especially as it affects veterans. As she told Glamour magazine, "I think it's really important to take the stigma away from mental health."

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## NOTES

1. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed. (Arlington, American Psychiatric Publishing, 2013), 165.
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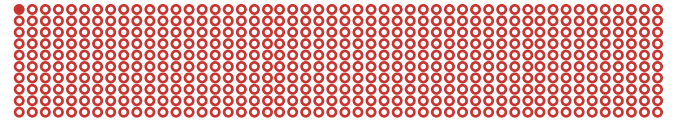


# MICROCEPHALY

WITHOUT MICROCEPHALY



WITH MICROCEPHALY



**2-12** babies out of every 10,000 live births are born with microcephaly. There is likely a higher occurrence in areas where disease and poverty rates are high. <sup>1</sup>

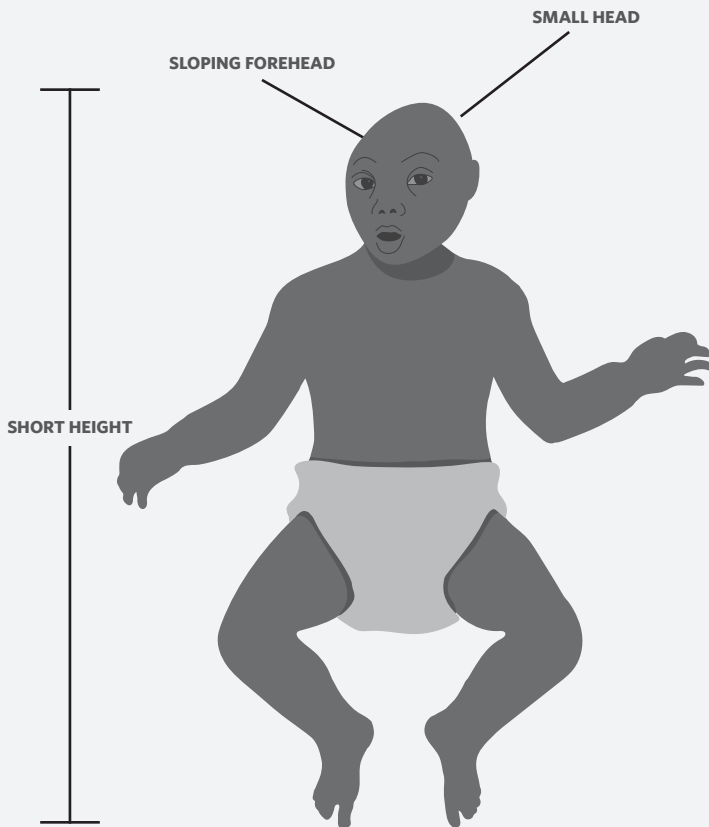
One open dot = 10

## DESCRIPTION <sup>2, 3, 4, 5</sup>

Microcephaly is a condition where a baby has a head and brain size much smaller than other children of the same age and sex.

## SIGNS AND SYMPTOMS <sup>6, 7, 8, 9, 10, 11</sup>

There is wide variation in the type and severity of symptoms people experience.



SPEECH CHALLENGES



LEARNING CHALLENGES



DIFFICULTY WITH BALANCE



DELAYED SITTING, STANDING, CRAWLING, AND WALKING



VISION PROBLEMS



HEARING PROBLEMS




SEIZURES (FITS)




DIFFICULTY SWALLOWING


## POSSIBLE CAUSES AND RISK FACTORS <sup>12, 13</sup>




**INFECTION**  
during pregnancy




**MALNUTRITION**  
pregnant mother or child not getting enough food or nutrients




**EXPOSURE**  
to alcohol or drugs during pregnancy



**OXYGEN DEPRIVATION**  
during pregnancy or delivery




**FAMILY MEMBERS**  
with microcephaly




**DISABILITIES**  
like Down syndrome

## INTERVENTIONS <sup>14, 15</sup>


### Professional




**MEDICATION**  
FOR SYMPTOMS



**PHYSICAL**  
THERAPY



**SPEECH**  
THERAPY



**SPECIALIZED**  
EDUCATION

### Family/Community



**HOME-BASED**  
THERAPY



**DAILY PLAY**



**HEALTHY DIET**



**DO NOT**  
MOCK OR STARE



**DO NOT ABUSE OR**  
PHYSICALLY PUNISH



**JOIN/FORM A**  
SUPPORT GROUP



### CHARO FAMILY

Kadzo was told she had children with microcephalus because demons came upon her when she was pregnant. She tried going to local healers for help but was unsuccessful. She was isolated and in such despair that she wanted to take her own life.

Participating in a parent workshop sponsored by Kupenda/Kuhenza showed her that she was not alone. She also discovered the true biological causes of her children's microcephaly.

Today, her sons are in school and Kadzo is the leader of a parent support group. She spends her time teaching other families that their children with disabilities can go to school and be a part of the community, too.

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## NOTES

1. Deborah Fields, "Microcephaly Epidemiology," News Medical, last modified December 30, 2022, <https://www.news-medical.net/health/Microcephaly-Epidemiology.aspx#:~:text=Globally%2C%201%20in%20every%2030%2C000,per%2010%2C000%20of%20live%20births.>
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10. "Facts About Microcephaly," Centers for Disease Control and Prevention.
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# MUSCULAR DYSTROPHY



One open dot = 10

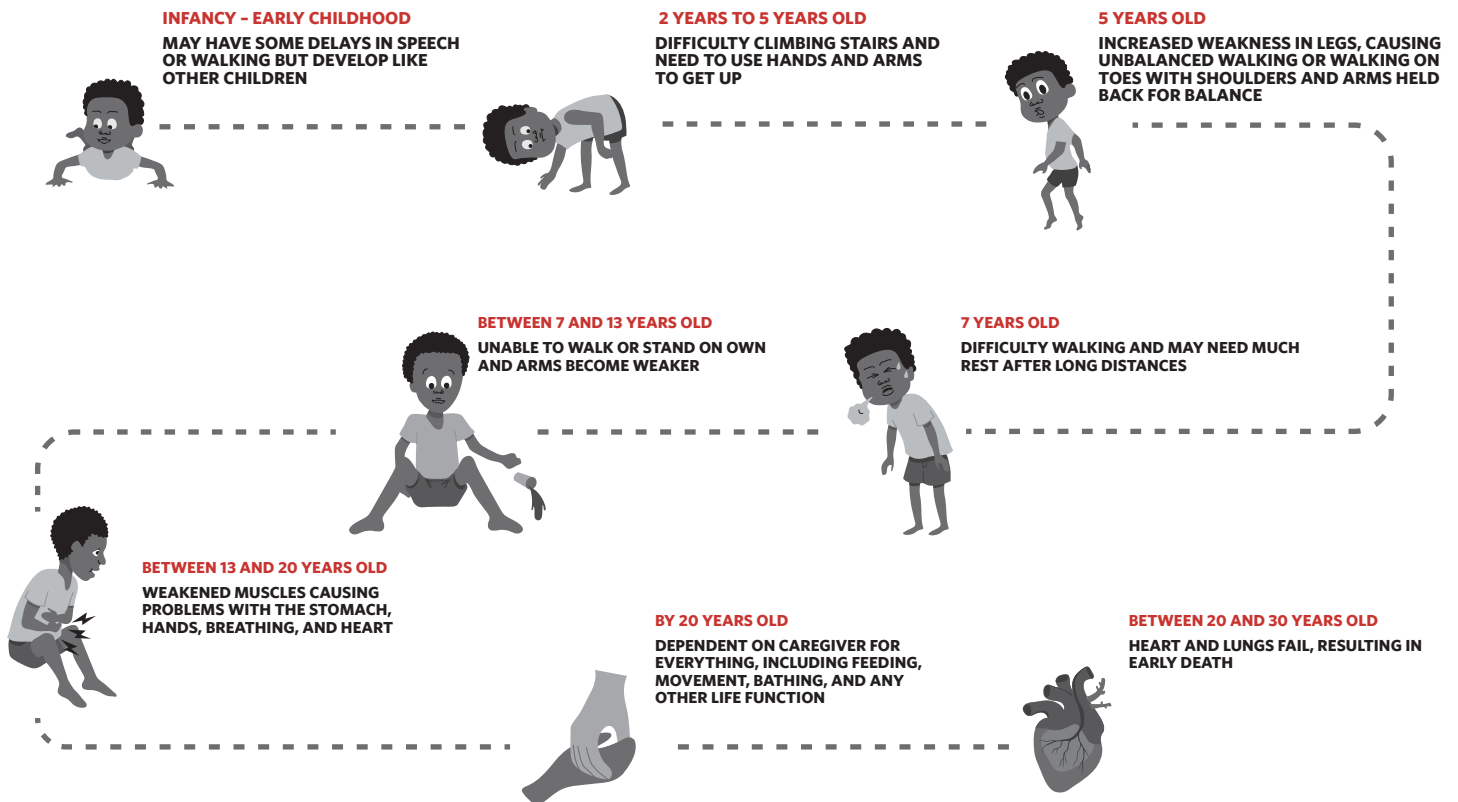
1 out of every 5,600 to 7,700 people have Duchenne's form of muscular dystrophy.<sup>1</sup>

## DESCRIPTION<sup>2, 3, 4</sup>

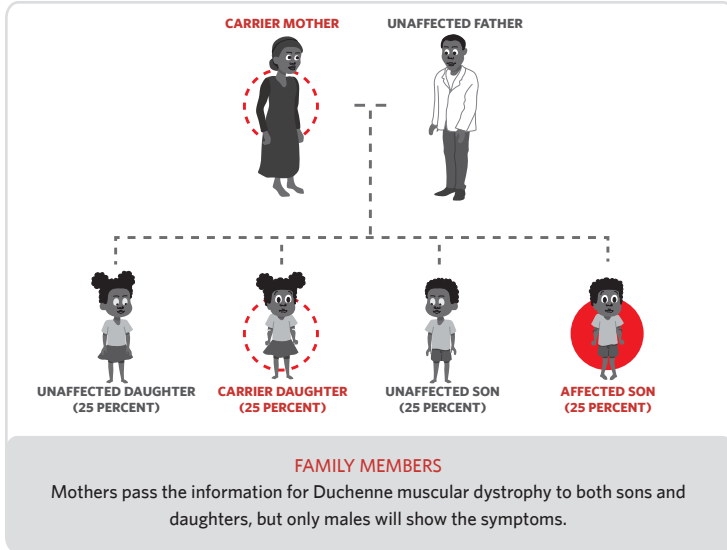
A group of inherited diseases that cause the muscles to become weaker over time, eventually limiting the use of arms and legs in addition to weakening the lungs and heart. There are several types of muscular dystrophy, but Duchenne's is the most common and severe. Becker's is similar, but symptoms usually show up in the teen years.

## SIGNS AND SYMPTOMS<sup>5, 6, 7</sup>

Depending on the type of muscular dystrophy, children can show symptoms as early as 2 and as late as 25-years old. Before the onset of symptoms, they develop like any other child. Duchenne muscular dystrophy is the most common type, with clear signs occurring sometime between 7-12 years. Duchenne's is what is detailed below.



## POSSIBLE CAUSES AND RISK FACTORS <sup>8,9</sup>



- Only males have the condition
- Mothers carry information (genes) for the condition but do not have it themselves (carrier)
- May have family members with the condition
- May occur without any family members having it



## GERALD

As a young child, Gerald was able to run around his village. By the age of 6, however, he was struggling to walk. By the age of 10, he was in a wheelchair. As his condition got worse, his family was ridiculed, accused of witchcraft, and threatened with harm.

Often, others did not realize that Gerald was intelligent and loved to learn. Although he studied and took exams while lying down, his scores were at the top of the class.

Kupenda/Kuhenza educated his community about muscular dystrophy and how it would eventually take his life. His community began assisting him to get to and from school and aided his family with household chores.

In January of 2021, Gerald died in his early twenties, as is common for people with muscular dystrophy. He died surrounded by love.

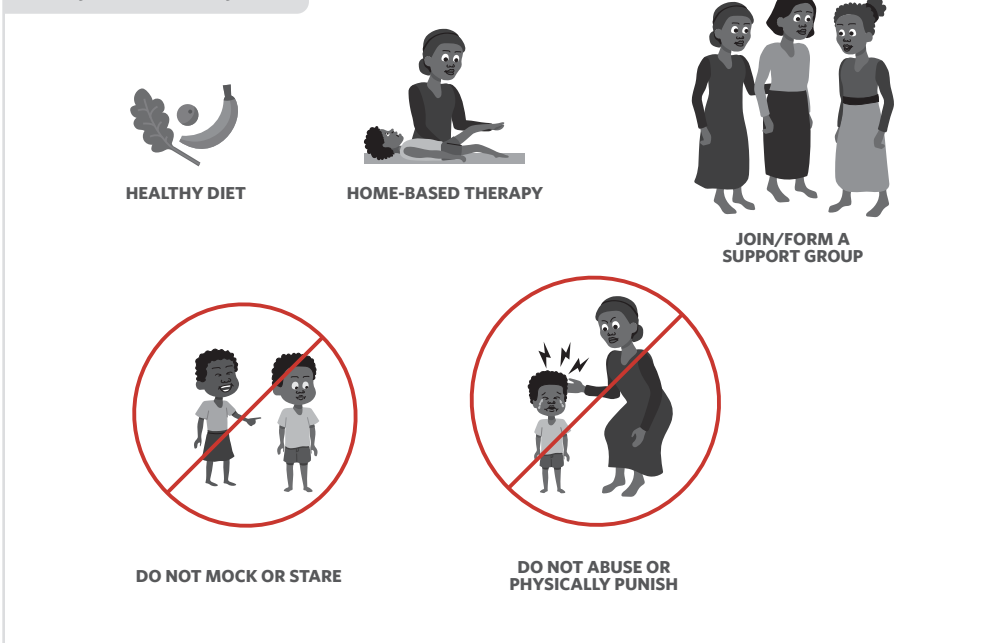
Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## INTERVENTIONS <sup>10, 11, 12, 13</sup>

### Professional



### Family/Community



## Kuhenza for the Children

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## INTERVENTIONS CONTINUED . . .

Family/Community (For those who are unable or have difficulty moving on their own)



**CHANGE THEIR POSITION OFTEN**



**ENSURE THEY HAVE CLEAN CLOTHES**



**BATHE THEM AFTER SOILING THEMSELVES**



**PROVIDE PAMPERS (NAPKINS)**



**PROVIDE ASSISTANCE DEVICES**



**USE TOILET ADAPTATION DEVICES**

## NOTES

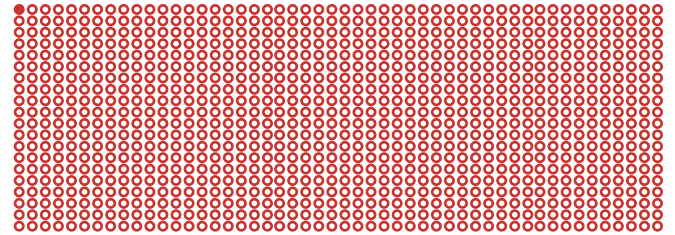
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2. "Muscular Dystrophy," National Institute of Neurological Disorders and Stroke, accessed February 15, 2023, <https://www.ninds.nih.gov/health-information/disorders/muscular-dystrophy>.
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10. Werner, *Disabled Village Children*, 110.
11. Watson, "Understanding Muscular Dystrophy—Symptoms."
12. "Caring for Someone with Duchenne Muscular Dystrophy," Duchenne and You.
13. Werner, *Disabled Village Children*, 110.



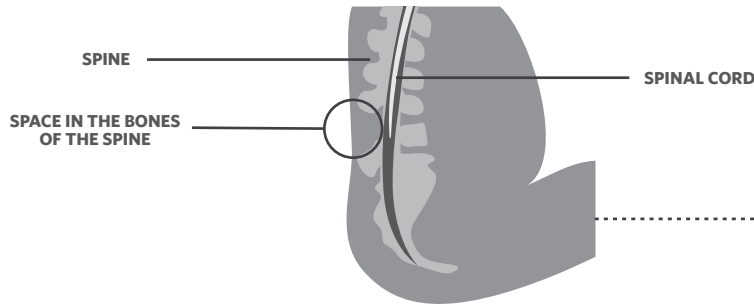
# SPINA BIFIDA (SB)

## DESCRIPTION <sup>4, 5, 6</sup>

Spina Bifida (SB) is a condition where there is a hole in the backbone that often causes damage to the spine and nerves in the back.

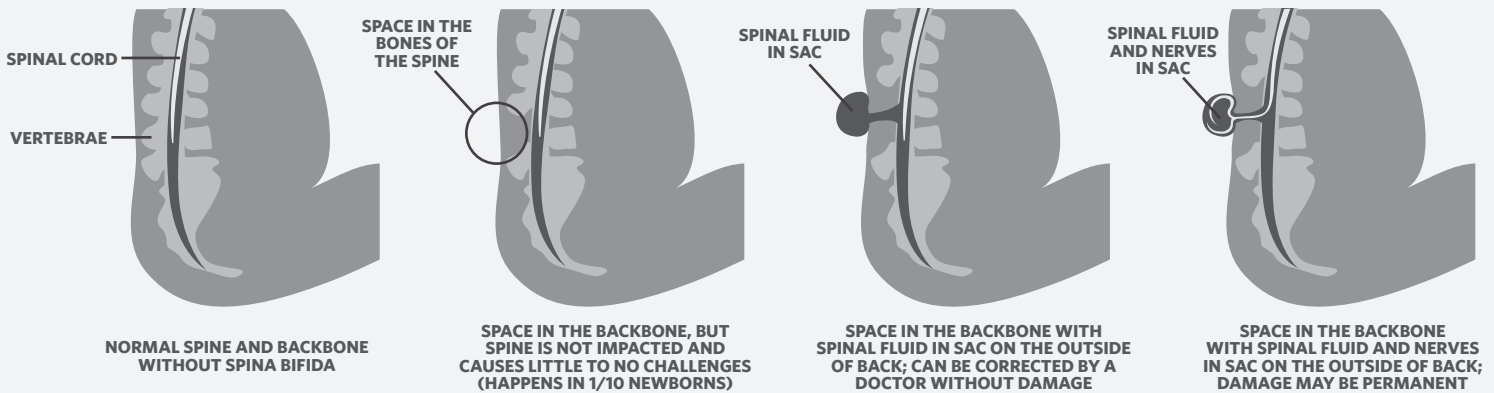


**1** out of every 1,000 infants is born with disabling spina bifida (SB). <sup>1, 2, 3</sup>



## SIGNS AND SYMPTOMS <sup>7, 8, 9</sup>

There is wide variation in the type and severity of symptoms people experience.



Abilities are determined by the type of SB as well as the size and location of the hole in the back.



DELAYED SITTING, STANDING, CRAWLING, AND WALKING



DIFFICULTY WITH BALANCE



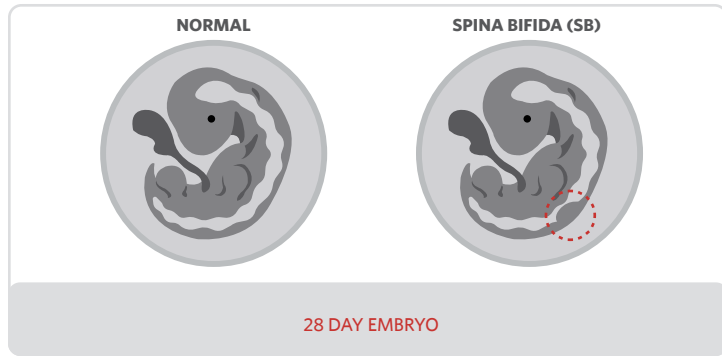
HYDROCEPHALUS (FLUID ON THE BRAIN)



PROBLEMS WITH BOWEL AND BLADDER CONTROL

## POSSIBLE CAUSES AND RISK FACTORS <sup>10, 11, 12</sup>

The reason for spina bifida is unknown.



During the first weeks of pregnancy, the hole forms for unknown reasons. This is before most women know they are pregnant.

## INTERVENTIONS <sup>13, 14, 15</sup>

The type of intervention depends on the severity and location of the hole in the spine. They may or may not benefit from...

### Professional



PHYSICAL THERAPY



SURGERIES

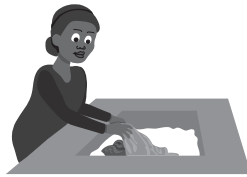


ASSISTANCE DEVICES

### Family/Community (For those who are unable or have difficulty moving on their own)



CHANGE THEIR POSITION OFTEN



ENSURE THEY HAVE CLEAN CLOTHES



BATHE THEM AFTER SOILING THEMSELVES



USE TOILET ADAPTATION



PROVIDE PAMPERS (NAPKINS)



ASSISTANCE DEVICES



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH



JOIN/FORM A SUPPORT GROUP



## BULELWA <sup>16</sup>

Bulwewa was born in 1975 with spina bifida. She attended a primary school for special needs but later attended a mainstream high school. She completed an executive secretarial course at K Commercial College and is now a chief administrator in the information systems department at Transnet in Saldanha Bay. In 1998, Bulelwa gave birth to a baby boy, who is now 16 years old.

For most of her life, Bulwewa walked with the aid of crutches, until a hip injury in 2009 forced her to use a wheelchair. She concludes, "My spina bifida is not an obstacle on living my life and reaching for my dreams. Whatever I do, my mother supports me, she believes in me, gives me space, and allows me to fall."

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## NOTES

1. Hsin-Hsiao S. Wang et al., "Emergent Care Patterns in Patients with Spina Bifida: A Case-Control Study," *J Urol* 193, no. 1 (January 2015): 268-273.  
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[http://www.scielo.org.za/scielo.php?script=sci\\_arttext&pid=S0256-95742014000400034](http://www.scielo.org.za/scielo.php?script=sci_arttext&pid=S0256-95742014000400034).



# SPINAL CORD INJURY



1 out of every 15,000 people has a spinal cord injury.<sup>1</sup>

One open dot = 100

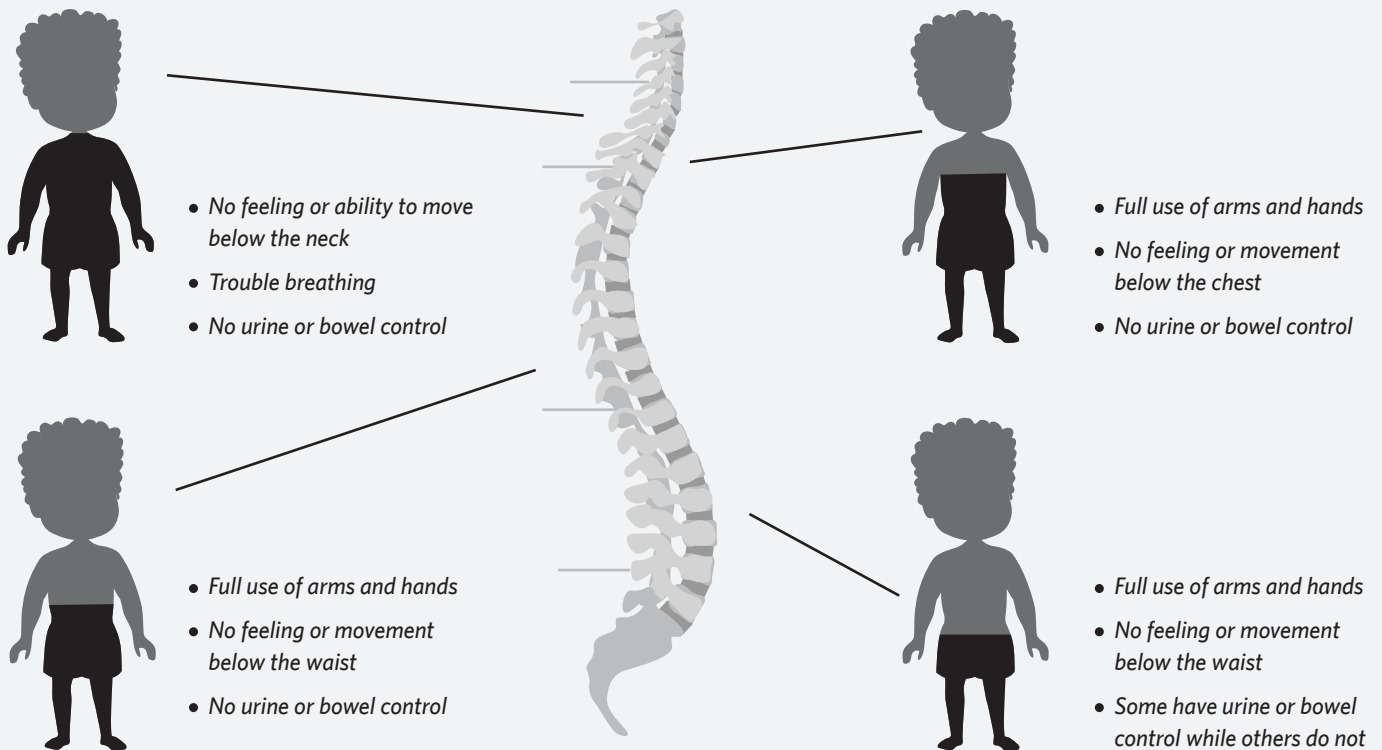
## DESCRIPTION <sup>2, 3, 4, 5</sup>

A spinal cord injury is damage to the bundle of nerves that carry messages between the brain and the rest of the body. This results in temporary or permanent changes to a person's ability to move or feel. The location and severity of the injury determines the particular areas of the body that will be affected.

## SIGNS AND SYMPTOMS <sup>6, 7, 8</sup>

*(The function and pain of a spinal cord injury depend on where and how much the nerve has been damaged.)*

SPINAL CORD INJURIES AND EFFECT  
*(The higher the injury in the spine, the more severe the effect.)*



## POSSIBLE CAUSES AND RISK FACTORS <sup>9, 10</sup>



**INFECTION**  
from diseases that impact the spine  
(ex.: meningitis or polio)



**INJURY**  
to the spine



**PROBLEMS**  
with bones growing incorrectly and damaging the spine

## INTERVENTIONS <sup>11, 12, 13</sup>

When an injury does not fully disconnect the spinal cord, there is more function and potential for improvement over time. However, when a spinal cord injury completely cuts the nerves, it cannot be repaired.

### Professional



**MEDICATIONS**

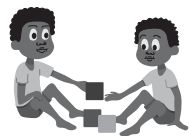


**PHYSICAL THERAPY**

### Family/Community



**HOME-BASED THERAPY**



**DAILY PLAY**



**HEALTHY DIET**



**JOIN/FORM A SUPPORT GROUP**



**DO NOT MOCK OR STARE**



**DO NOT ABUSE OR PHYSICALLY PUNISH**



## STEPHEN

At ten years old, Stephen Kitsao was paralyzed from the waist down when he fell from a coconut tree. His community told him his disability was a curse, and that he would never accomplish anything.

According to Stephen, "The doctors had said that I would not walk again. This means that I was not going to school and play[ing] with my friends like before. I started asking myself hard questions. Having found no answers, I slowly found myself in a state of denial which would last for some time. During this state, I would remain indoors and even refuse to eat my food. Life had no meaning to me."

In spite of negative stigmas in his community about disability, Stephen's family worked hard to connect him to the right resources and medical treatment. When they found Kupenda/Kuhenza, Stephen was able to receive a wheelchair, medical care, schooling, and counseling.

With this support, Stephen went on to earn a scholarship to Kenyatta University. There he excelled in his studies and majored in special needs education and journalism. With this new skill set as well as his own experiences, Stephen hopes to improve the lives of others.

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## INTERVENTIONS CONTINUED . . .

Family/Community (For those who are unable or have difficulty moving on their own)

Most people with a spinal cord injury have difficulty moving on their own. Depending on the severity of their condition, they may need some of these supports:



**ENSURE THEY HAVE  
CLEAN CLOTHES**



**CHANGE THEIR  
POSITION OFTEN**



**PROVIDE PAMPERS  
(NAPKINS)**



**USE TOILET ADAPTATION**



**BATHE THEM AFTER  
SOILING THEMSELVES**



**PROVIDE ASSISTANCE  
DEVICES**

## NOTES

1. "Spinal Cord Injury," World Health Organization, last modified November 19, 2013, <https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury>.
2. David Werner, *Disabled Village Children* (Berkeley: Hesperian Health Guides, 2018), 175.
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12. "Spinal Cord Injury," National Institute of Neurological Disorders and Stroke.
13. "Spinal Cord Injury," World Health Organization.



# SPINE CURVATURE DISORDERS



Up **3** out of every 100 people have some kind of spine to curvature disorder.<sup>1</sup>

## DESCRIPTION<sup>2,3</sup>

An irregular curvature of the spinal column that can create a C or S shape (Scoliosis), a curve in the lower back towards the front of the body (Lordosis), or a more than 50% curvature or hump in the upper back (Kyphosis).

## SIGNS AND SYMPTOMS<sup>4,5</sup>

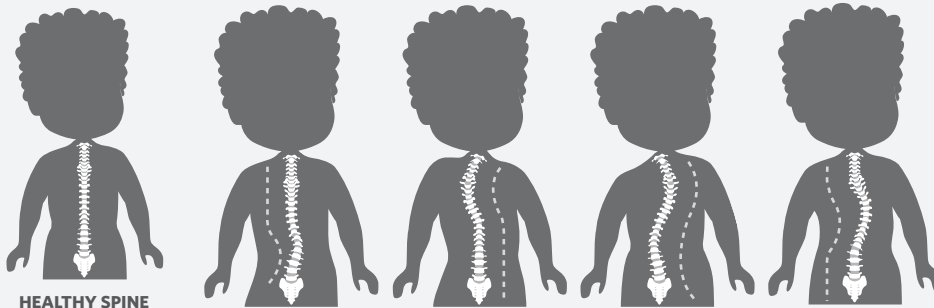
*(There is wide variation in the number, type, and severity of signs and symptoms people experience.)*

### MAIN TYPES OF SPINE CURVATURE DISORDERS:

#### SCOLIOSIS

A 'C' or 'S' curvature of the spine causing uneven shoulders, hips, and leaning to one side

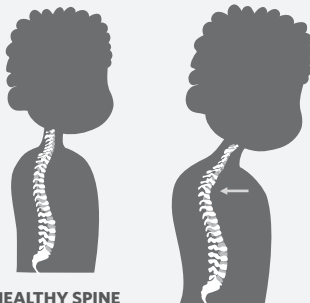
*(Rotoscoliosis includes a sideways curvature as well as a strong degree of rotation or twist.)*



HEALTHY SPINE

#### KYPHOSIS

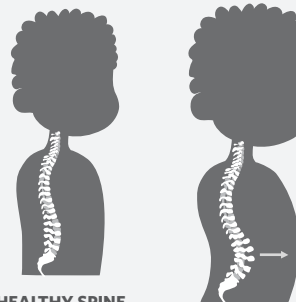
An excessive curvature between the shoulders causing a hunching of the back



HEALTHY SPINE

#### LORDOSIS

Increased inward curvature of the lower part of the spine



HEALTHY SPINE



BACK PAIN



BREATHING PROBLEMS

## POSSIBLE CAUSES AND RISK FACTORS <sup>6,7</sup>



**FAMILY MEMBERS**  
with spine differences



**MANY UNKNOWN CAUSES**  
The causes of most spine deformities are unknown.



**INFECTION**  
from diseases that impact the spine (tuberculosis, etc.)



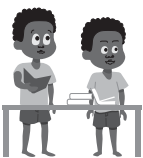
**OTHER CONDITIONS**  
impact the spine like cancer, dwarfism, spina bifida, broken bones, muscular dystrophy, bone disease, etc

## INTERVENTIONS <sup>8,9,10</sup>

### Professional



### Family/Community



### NEEMA

Neema is a 23-year-old young woman who developed kyphoscoliosis at a young age.

As her spine started to curve, she developed a hunching of her upper back that affected the alignment of her shoulders and hips. Since her challenges were discovered later in life, surgical interventions were too risky to her mobility. However, her condition did not prevent her from finishing secondary school and looking into her next steps for education.

Today Neema enjoys being active in her community, where she is loved and accepted for her kindness and determination.

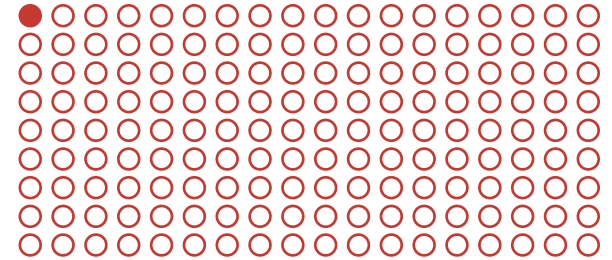
Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

**NOTES**

1. "Scoliosis," American Association of Neurological Surgeons, accessed April 17, 2023, <https://www.aans.org/Patients/Neurosurgical-Conditions-and-Treatments/Scoliosis#:~:text=Incidence%20and%20Prevalence,occurring%20equally%20among%20both%20genders>.
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# TOURETTE SYNDROME



## DESCRIPTION <sup>2,3</sup>

This condition typically starts to appear between 5 to 10 years old and is characterized by tics, which are repeated involuntary movements or sounds.

**1** out of every 162 people have this syndrome.<sup>1</sup>

## SIGNS AND SYMPTOMS <sup>4,5,6</sup>

*(There is wide variation in the type and severity of symptoms people experience.)*

### REPEATED BODY MOVEMENTS LIKE:



SHRUGGING SHOULDERS



INCREASED BLINKING



NECK STRETCHING



MOUTH MOVEMENT



SPITTING

### REPEATED SOUNDS LIKE :



WORDS OR PHRASES



HUMMING



GRUNTING



SNIFFING



COUGHING NOT RELATED TO ILLNESS

*Note: For some with Tourettes, their tics may include inappropriate words, phrases, or gestures that seem rude, but the person is not in control of these tics.*

## TRIGGERS <sup>7,8</sup>

*Avoiding these triggers may reduce the amount of tics a person with tourette's experiences.*



STRESS



BEING TIRED



BEING EXCITED



ILLNESS



## POSSIBLE CAUSES AND RISK FACTORS <sup>9, 10</sup>



**FAMILY MEMBERS**

about 50% of parents who carry the information for this disorder pass it on to their children



**INFECTION**

in child or mother (before birth)



**PREMATURE**

child is born too early



**PROBLEMS**

during birth

## INTERVENTIONS <sup>11, 12</sup>

### Professional

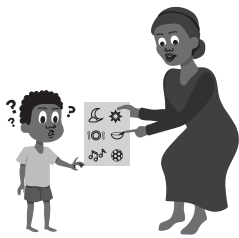


MEDICATIONS

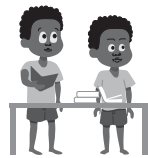


BEHAVIOR THERAPY

### Family/Community



PATIENCE AND UNDERSTANDING



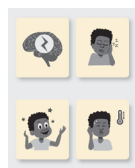
ENROLL IN MAINSTREAM SCHOOL



EDUCATE OTHERS (COMMUNITY, TEACHERS, ETC.) ON THE CONDITION



JOIN/Form A SUPPORT GROUP



AVOID TRIGGERS (SEE PREVIOUS PAGE)



DO NOT MOCK OR STARE



DO NOT ABUSE OR PHYSICALLY PUNISH



### MIKE <sup>13</sup>

“My name is Mike Higgins and I am a father, a pastor, a husband, a dean of students of a seminary, a minister, a full colonel in the United States Army, and I have Tourette syndrome.

The first time I heard the word, ‘Tourette syndrome,’ from the doctor I had no idea what he was talking about. I had never heard of it. I didn’t know anybody who had ever heard of it before. There were a lot of days as a 12 year-old when I would lay in bed and think about what was happening to me that I could not control. It caused me to wonder, ‘Why was I born like this?’

I think that I was not diagnosed until I was 28 years old because our family doctors didn’t know about Tourette syndrome. Finally, I met a neurologist who asked me if anybody in my family had ever had this. I told him that my grandfather did. And he said, ‘I think I know what you have.’

I didn’t think that I was ever going to be married because it seemed like it was hard enough to just be single with Tourette syndrome. But in my family life now, it’s just who I am.”

Art Director: Amy Allaire | [www.amyallaire.com](http://www.amyallaire.com)  
Graphic Designer: Siwen Tao | [www.siwentao.com](http://www.siwentao.com)

## NOTES

1. Melissa Fink, "5 Things You Need to Know About Tourette Syndrome, Banner Health, last modified May 24, 2020, <https://www.bannerhealth.com/healthcareblog/teach-me/five-things-to-know-about-tourette-syndrome#:~:text=Tourette%20Syndrome%20by%20definition%20starts,162%20children%20have%20the%20disorder>.
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