

THROUGH VHL RESEARCH

CURING CANCER

VHL Kids' Handbook



THE VHL KIDS' HANDBOOK

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Chapter 1: INTRODUCTION

What is this book about?

The VHL Kids Handbook was written for kids of all ages. This book will help you and your parents learn about von Hippel-Lindau disease or VHL. Perhaps you or a loved one has VHL. This book will explain in simple terms what VHL is, how people get it, and how people live with it.

Read this book with your parents so they can explain things to you and answer any questions that you may have. If you'd like, you can read one chapter at a time, or choose to jump ahead to the chapters that interest you most. Do not feel like you have to read the whole book at once because there is a lot of information to be learned. You may also decide to read certain chapters again at a later point in time. You and your parents can use this book however you like.

You will find a lot of new words. Don't worry: we explain these new words at the end of the book in the Word List Glossary. You will also find some questions that are underlined. These are questions that kids with VHL might ask. The answers to these questions can be found in the paragraphs directly below.

We hope that this book will help you better understand VHL. This book is meant to leave you with a positive feeling about VHL so that you can continue to live your life to its fullest!

Chapter 2: WHAT IS VHL?

What is VHL?

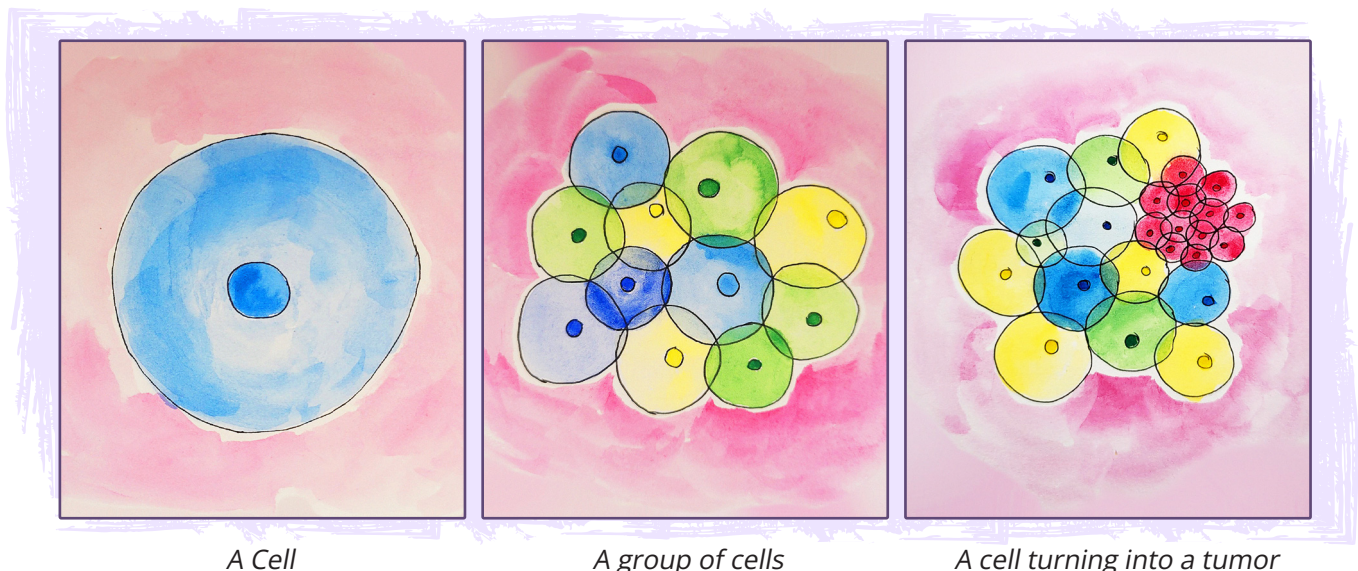
VHL stands for von Hippel-Lindau disease. It is named after two doctors who first discovered it: Dr. Eugen von Hippel and Dr. Arvid Lindau. VHL is a rare disease, which means that, when compared to other diseases, there are not many people who have it. Even though it is rare, there are thousands of people around the world who have VHL.

Just because a person has VHL does not mean that they are sick. Most people with VHL usually feel fine. Having VHL means that you have a greater chance of developing tumors or cysts in certain parts of your body than people without VHL.

What are tumors?

Our bodies are made up of millions of cells. Each cell has an important job to do, such as being a skin cell, a brain cell, or a kidney cell. Healthy cells normally make copies of themselves as they grow. But, if a kidney cell starts growing faster than normal, a tumor can form in the kidney. A tumor is a clump of cells that do not behave like normal cells anymore. With people who have VHL, their tumors grow like small knots bunched together.

People with VHL can also grow cysts, which are not tumors. A cyst is a collection of fluid or liquid that can be found in different parts of the body. People with VHL might grow cysts in their kidneys or pancreas. These cysts usually do not cause health problems, and the organs usually work normally.



What kinds of tumors can someone with VHL get?

People who have VHL may have tumors in different parts of their body. These tumors could be found in the following areas:

Brain: Your brain is inside your head. It is the control center for your nervous system. Your brain helps you think, and it controls how your body works.

Spinal cord: Your spine is a set of bones, like a stack of rings, that runs down your back. Your spinal cord is like a wire that runs through these rings. It carries signals from your brain to the rest of your body.

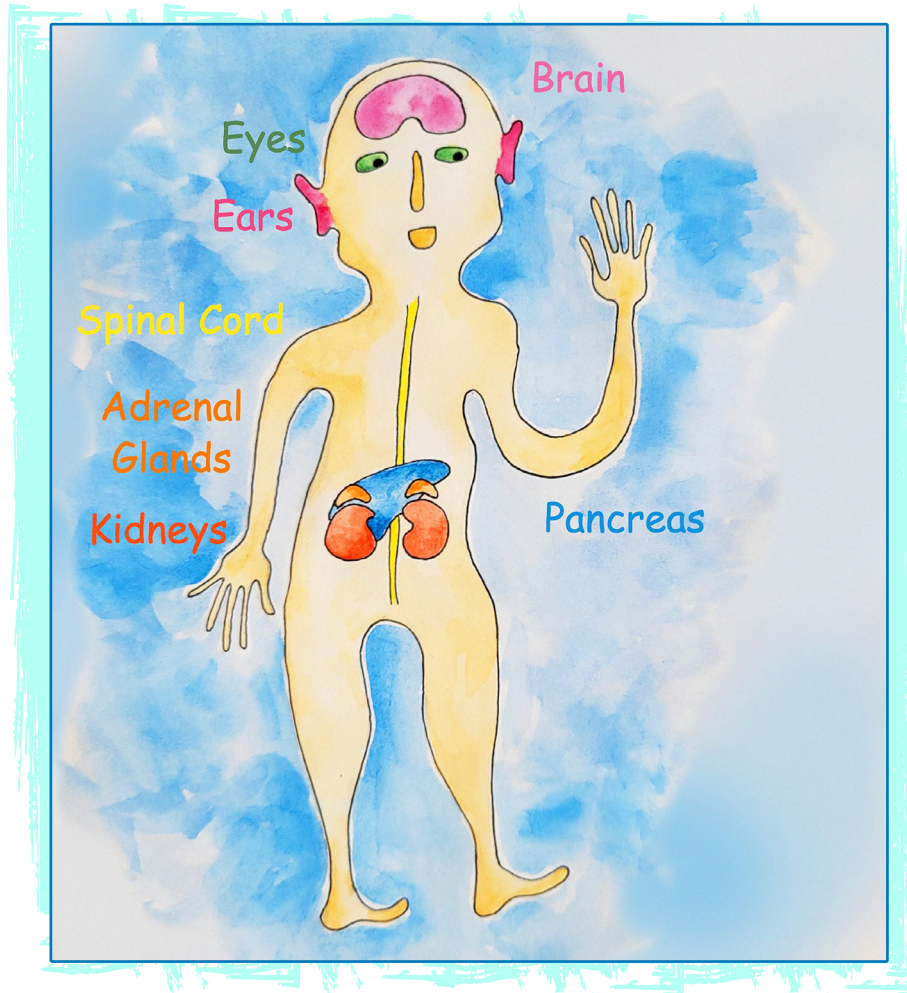
Eyes: Your eyes are your organs of sight. They allow you to see and detect light.

Ears: Your ears are your organs of hearing. They allow you to listen to sounds. They play a role in your sense of balance too!

Kidneys: You have two kidneys. They are located in your abdomen, or stomach area. They filter your blood and get rid of waste products by turning them into urine.

Adrenal glands: You have two adrenal glands that sit on top of your kidneys. They control your hormones, or chemical messengers, that send signals from one cell to another.

Pancreas: Your pancreas is an organ located behind your stomach. It helps your stomach digest food.



Do all people with VHL grow tumors?

- Some people may have a few tumors during their life, some people may have more, and some people may never have any.
- Some people may only grow tumors in one part of their body. Other people might grow tumors in more than one part of their bodies.
- Some people may have tumors grow in a part of their body more than once.

If you get a tumor you don't have to be scared. Your doctors will watch it closely in order to make sure it does not cause a problem.

People with VHL are not the only ones who get tumors. Anyone can get a tumor anywhere in their body whether they have VHL or not.

Do people with VHL get cancer?

Sometimes tumors turn into cancer, and other times they do not. Cancer happens when certain types of tumors grow too much and spread to places in the body that they should not. Most of the time, VHL tumors are not cancerous.

Chapter 3: HOW DO PEOPLE GET VHL?

VHL is a hereditary disease, which means that it is found in families. It can be passed from your grandparents to your parents to you. If you have VHL, it is likely that one of your parents has it too. A parent with VHL can pass it along like any other trait, like eye color, without knowing it. You may have other family members who also have VHL, like a grandparent, brother, sister, aunt, or uncle. VHL is not the only disease that is found in families. There are many other diseases that are hereditary as well.

You cannot get VHL from another person by touching them or catching it like a cold. Every person with VHL is born with it.

In some cases, VHL might not be passed on from a parent to a child. Sometimes, they are the very first person in their family to have VHL. This does not mean that they did anything that caused them to have VHL; they were just born that way. It may help to talk with other kids who have VHL, and Chapter 10 will give you information on how you can communicate with them.

How do I know if I have VHL?

You may have already had symptoms of VHL and were checked by your doctor. A symptom is a feeling, sensation, or pain that usually makes you feel different than how you normally feel every day. It is also possible that you do not have any symptoms, but you have a family member who has VHL. In both cases, you and your parents may want to test for VHL so that your doctors can make sure that you are taken care of.

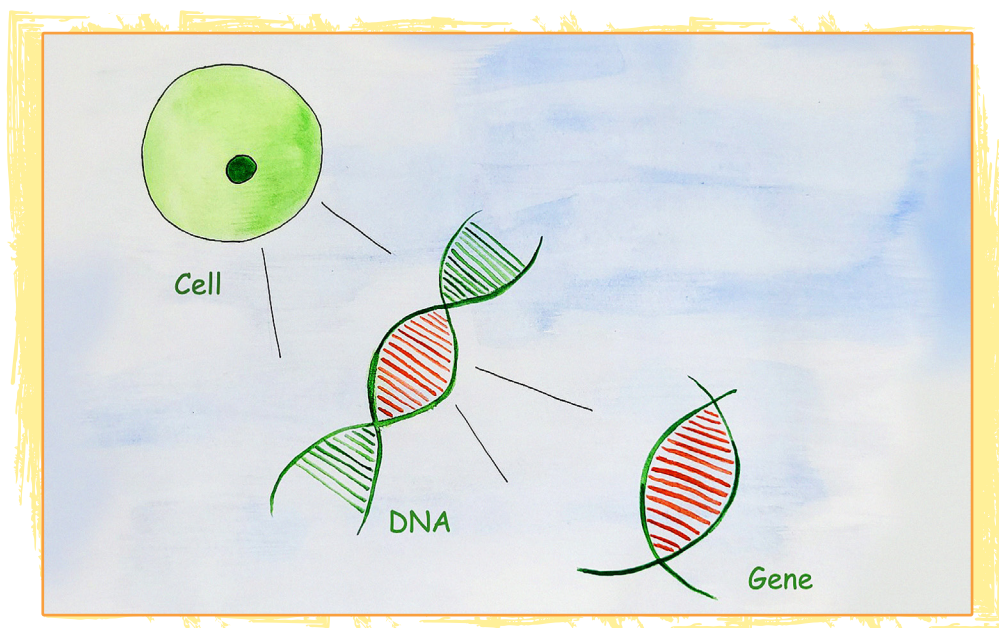
The only true way to know if you have VHL is to have genetic testing done. Genetic testing is explained in Chapter 4. You and your parents, doctor, and genetic counselor will decide if this test is right for you.

CHAPTER 4: WHAT ARE DNA AND GENES

There are a few important things to learn if you want to understand how genetic testing works. VHL is a hereditary disease. DNA and genes are responsible for how we inherit traits, like eye color, hair color, or even VHL, from our parents.

What is DNA?

DNA stands for deoxyribonucleic acid. This can be hard to remember so we just call it DNA. Your body is made up of millions of cells and each one has DNA. The DNA is very tiny, and you are unable to see it, but it is inside of you. Under a microscope it looks like a long curly ladder.



What are genes?

Your genes are chunks of DNA that help to make up the long curly ladder. Genes are a special code that carry the directions for how your cells should work. Genes are the instructions your body follows on how to create you! You have all kinds of different genes in your body. Some of your genes will tell your cells how to be skin cells or heart cells. Each gene has a special job to do.

You were born with two copies of every gene in your body, one copy from each of your parents. It is estimated that a person has **50,000** genes in their body!

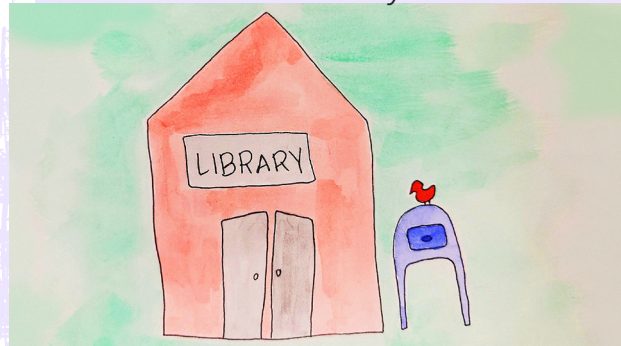
You have genes that contribute to traits like hair color or eye color. Sometimes one gene is responsible for a trait while other times multiple genes contribute to a trait. Your parents pass their genes onto you, which makes you a very special person!

How do DNA and genes work in my body?

Think of DNA in your cells like a library full of books. The DNA in your cells is divided into sections called genes. Genes are like books in a library that are made up of words and letters. Each gene carries instructions to tell your cells how to do their job, and how to keep you healthy.

Just like a spelling mistake can happen in a book, there can be a change in a gene in a person. This is called a gene mutation. That is what causes VHL, like a tiny spelling mistake in a book. That means that the VHL book, or gene, does not make sense to the cells in your body.

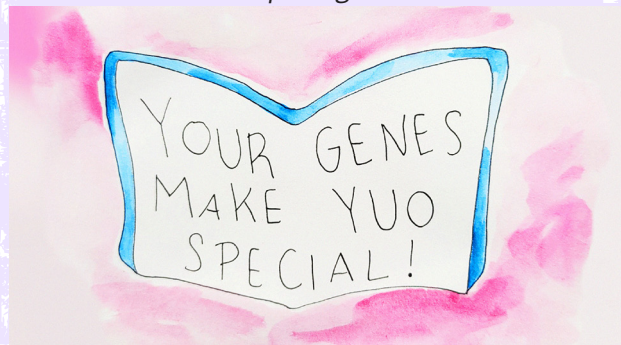
DNA = a library



Genes = books in a library



Gene Mutation = spelling mistake in a book



How do people get the VHL *gene* mutation?

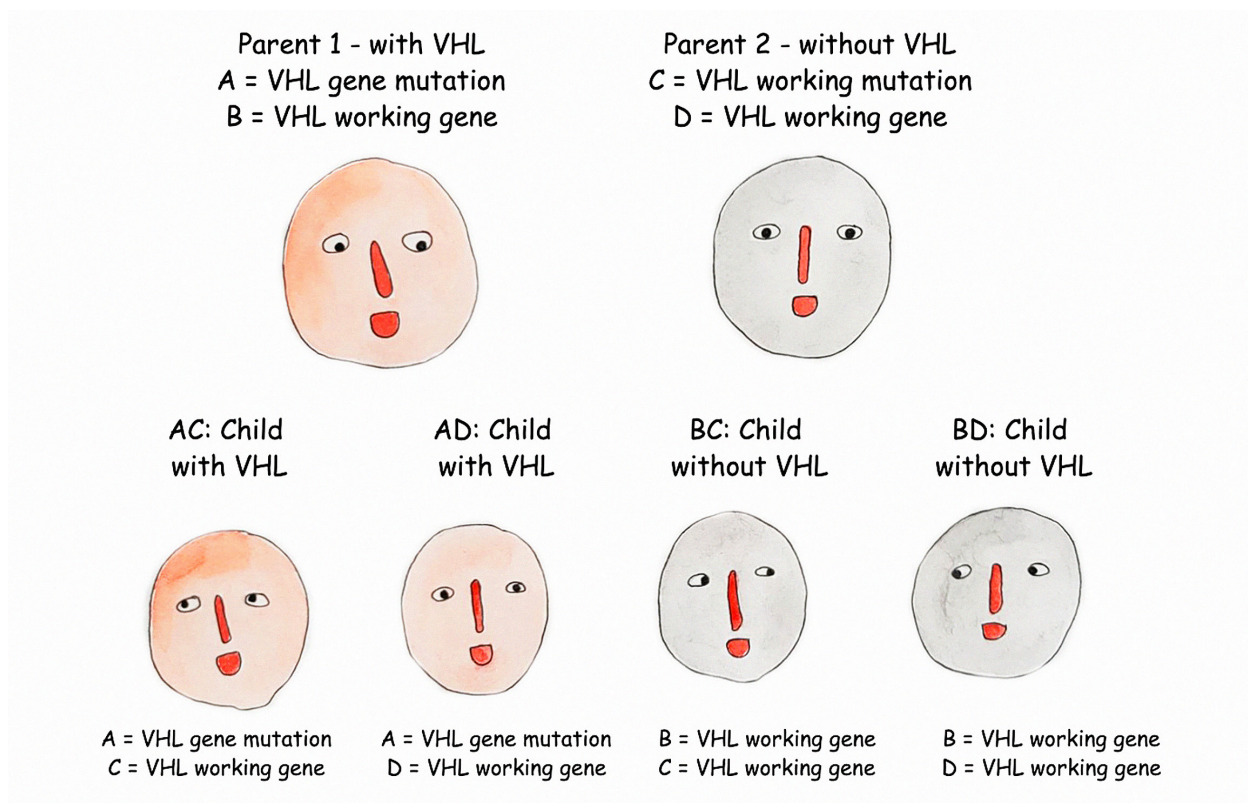
You have two copies of every gene in your body, one from each parent.

Every person has two copies of the VHL *gene*. But people with VHL have a gene mutation in one of their VHL *genes* that makes it stop working properly. When the VHL *gene* is working properly it helps to prevent tumors and when it cannot do its job, tumors can grow.

Every time a baby is born to a parent with VHL, there is a 50% chance that the baby will have VHL, and a 50% chance that the baby will not have VHL. It does not matter if the baby is the first child in the family, second, third, or fourth. The chance of getting the VHL *gene* mutation is the same every time a baby is born.

Therefore, if you have one parent with VHL, there are two possible outcomes.

- **You have VHL:** You have one copy of the VHL *gene* that works, and one copy of the VHL gene that has a mutation.
- **You do not have VHL:** You have both copies of the VHL *gene* that work. Your parent who has the VHL mutation passed their working copy to you.



How is genetic testing done?

Genetic testing is typically done with a blood test, which is a test where a small amount of blood is taken from your arm. Some people think it feels like a small poke on your arm. It does not hurt very much or for very long, especially if you relax. Genetic testing can sometimes be done with a cheek swab. This test is done using a small brush, like a Q-tip, and rubbing it on the inside of your cheek to pick up some of your cheek cells. The cheek swab does not work for all families, so your doctor will tell you which test is required to get the best information.

Your blood sample or cheek cells are examined in a laboratory to see if you have VHL. The test looks for the VHL *gene* mutation in one of your VHL copies, which is like looking for a spelling mistake in the VHL book.

There are two possible results of the genetic testing:

- **Positive** – this means that you have VHL (you have one working VHL *gene* and one VHL gene that does not work)
- **Negative** – this means that you do not have VHL (you have two working VHL *genes*)

What if I am nervous about the test?

The blood test might seem scary. That could be because you are learning new information about yourself even though you feel fine, or because you have symptoms, and you are worried about them. The important thing is to talk to your parents about these feelings. It might be hard to wait for the blood test results. Waiting can be difficult. You may have to wait a few weeks. If you can, try to get your mind off things for a while, it can help make waiting easier. Eventually, your doctor or genetic counselor will call your parents to talk about the results. Just remember that whatever the result is, it does not change who you are!

CHAPTER 5: WHAT HAPPENS IF I HAVE HVL?

What happens if I have VHL?

If you have VHL, your doctor will do a physical exam to make sure that you stay healthy. The physical exam usually happens once every year. There are a set of guidelines that help your doctor figure out which tests are best for you depending on your age and your family background. Most of these tests will be done once a year too.

The tests your doctor orders are to monitor what is going on inside of your body. To monitor something means to keep close watch on it, and your doctor does this by running tests. We call these tests screenings. These tests usually do not hurt, but you might feel a little uncomfortable with some of them because they are strange or new to you. The doctor will be able to explain the tests to you before you have them done.

What kind of tests or screenings would I need?

Eye Exam: Most kids need to have their eyes checked regularly whether they have VHL or not. But, if you have VHL, you would need to see an ophthalmologist or retinal specialist who is an eye doctor. Eye doctors can look through your eyes to see what is going on behind them. Sometimes tiny tumors can hide out there, so your doctor will use a special magnifying lens called an ophthalmoscope to look at your eyes very closely.

The eye exam does not hurt. The doctor will shine a bright light into your eyes and ask you to look around in different directions. Before the exam, the doctor will put a few drops in your eyes to dilate them. The drops make your pupils (the small black center of your eyes) get slightly bigger. This will help your doctor to see your eyes better. You should bring sunglasses with you because your eyes might be sensitive to light afterwards, but this soon goes away.

Hearing Exam: You will also need a hearing exam by an audiologist. This is a fancy name for an ear doctor. It is like the hearing test given in schools; it just lasts a little longer. You usually have to wear headphones and listen for beeps. The test does not hurt at all. Some kids like to listen for the beeps!

Urine/Blood: Another test you will need to take is a 24-hour urine test or a blood test. These tests will be able to tell your doctor about possible tumors called pheochromocytomas, or pheos, that you might have on or near your adrenal glands. If you do the 24-hour urine test, you will have to pee into a cup for a whole day and pour it into a big jug each time, which you keep in your refrigerator. You will need to take the jug to a laboratory to be examined. During this test, it is a good idea to stay home so you do not forget to collect your urine.

If your doctor wants you to have the blood test done instead of the urine test, you will probably go to the laboratory. Sometimes your doctor will tell you not to eat for a few hours before taking the test. You may want to have the test done in the morning before breakfast so that you are not too hungry.

MRI – Abdomen, Brain, Spine: There are also some special x-ray machines that can see just about everything in your body from head to toe. One of these machines is called an MRI. The MRI is a big machine that you lay down in. It is very loud and noisy, but you will not feel anything. It is important to be very still when you have this test so the MRI machine can take clear pictures. Your doctor will usually give you earplugs so you will not hear the loud noises. Some places with MRI machines even let you listen to your favorite music during the test!

Sometimes in the middle of the test, your doctor may give you a small injection or shot of dye to highlight certain parts of your body on the pictures that the MRI machine is taking. For the most part, it is an easy test. Some people rest or take a little nap. You can even bring your teddy bear with you to hug.

You might have already had some of these tests or screenings. Some might be new to you. Others you might not be old enough for. Your doctors will make a plan for what tests or screenings you need as you get older.

CHAPTER 6: WHAT IF MY VHL SYMPTOMS CAUSE A PROBLEM?

What if my VHL symptoms cause a problem?

Most of the time, people with VHL feel fine, but you will need to have regular screenings, like we talked about in Chapter 5. Even if a tumor is found, it may not need to be taken out, and your doctor will keep a close watch on it.

Sometimes a tumor causes a person to have symptoms that they never had before. If you have a symptom that is caused by a tumor and does not go away, your doctor might say that you need to meet with a different doctor who knows how to take out or remove tumors. This special doctor may be a surgeon.

It is important to know that even if you have a tumor removed, you may have another tumor grow in the same place at another point in time. That sometimes happens with people who have VHL. But, as long as you keep up with your screenings, your doctor should be able to catch things early.

How are tumors treated or removed?

There are different ways to treat tumors. Your doctor and your parents will tell you more about the kind of treatment you might have if you ever need it. Different treatments are used for different types of tumors in the body. The area of the tumor will also determine the type of treatment you may have. For example, eye tumors can often be treated with a tiny laser aimed only at the tumor. Your doctors will talk to you about what you can expect during the treatment and after.

Sometimes doctors or surgeons use surgery to remove tumors. There are many different types of surgeries. Another word for surgery is operation. Usually, your doctor will give you a special medicine to make you fall asleep for a short time. During this time, your doctor will take out your tumor, but because you are asleep, you will not feel anything. It does take time to feel completely better after surgery, so you will need to rest and follow your doctor's instructions. During your recovery, it may be a good time to read a book or watch your favorite movie at home. After your tumor is removed you should feel better and back to normal very soon.

There are also non-surgical approaches to treating VHL tumors that are being studied. Recently, there was even a medication approved to treat certain tumors related to VHL in adults. It is possible that this medication will be used for children too in the future. As time goes on, more and more options will become available to avoid surgery.

What symptoms should I look out for?

It is important to tell your parents if you do not feel well or if you feel unusual at any time, even if it is something that is not bothersome. For example, if you are getting headaches more often or if your vision changes at all, then tell your parents right away. If you are not

with your parents, and you are feeling sick, be sure to tell the person responsible for you that you have VHL or that it runs in your family.

Maybe you have a symptom that does not seem important, maybe you think it will go away, maybe you want to ignore it, or maybe you are embarrassed to talk about it. A symptom you are feeling could be a clue to what is going on inside your body.

Just because you have a symptom does not mean that you have a tumor or that you need to be scared. The symptom or feeling may be related to VHL or it may not be. Your parents will know how to best help you, and they will know when you need to see your doctor. It is very important for everybody to pay attention to their bodies, not just people with VHL.

Here is a list of symptoms you should look out for:

- **Headaches:** If your head hurts and does not feel right at any time.
- **Vision Problems:** If your eyes are blurry, if you see spots, or if your vision does not seem normal at any time.
- **Hearing Problems:** If your hearing changes, if you are hearing less out of one ear than the other, or if your hearing does not seem normal at any time.
- **Vomiting:** If you throw up or feel sick to your stomach at any time.
- **Balance Problems:** If you feel like you cannot stand up straight, or if you feel dizzy at any time.
- **Pain:** If any part of your body hurts at any time.
- **Not Feeling Normal:** If you do not have energy, feel tired, if your heart beats really fast, if you are often sweaty, if you feel nervous, or just feel sick at any time.

CHAPTER 7: WHAT CAN I DO TO STAY HEALTHY?

Can I still be healthy and have VHL?

Yes! Most people with VHL live healthy and happy lives. The number one thing you can do to be in control of VHL is to visit your doctor every year for a physical exam and to have your screenings done on time. If you and your doctor are on top of your screenings, you should be able to catch any tumors or cysts early. This will make it easier for your doctor to monitor you and take care of any symptoms that you may have. Just remember to tell your parents if you do not feel well at any time so they can help you.

What else can I do to stay healthy?

Use your healthy habits! It is important for everyone, not just people with VHL, to eat healthy foods, exercise (if permitted by your doctor), and to get enough sleep. Eat plenty of fruits and vegetables and keep a balanced diet. If you keep your body as healthy as possible, it will be easier for you to fight off any problems with VHL if they ever come up.

Is there anything else I can do?

Keep a positive attitude! Keeping your mind healthy and happy is just as important as keeping your body healthy and happy. If you are ever feeling worried or unhappy about anything, talk about it with your parents, family members, teachers, doctors, friends, or a counselor. A counselor is a special person who talks to people of all ages to help them feel better inside. Talking about any type of problem with someone can make you feel better. People are here to help you!

CHAPTER 8: HOW WILL VHL CHANGE MY LIFE?

Will VHL change my life?

All kids have different feelings about having VHL. Your everyday life might not really change, and you will still be the same person you were, but the way you think about things may change. You may have different feelings about things at different times. There may be times that you will not even think about it, and there may be times that you will.

You may feel:

- Like you are the only kid with VHL.
- Mad and upset that you have VHL.
- Sad that you have VHL.
- Like life is not fair.
- Afraid that VHL might make you sick in the future.
- Scared about having tests or surgery.
- Tired of doing tests and visiting doctors.
- That VHL is a really big problem and too much to handle.
- That VHL is not really a big deal.
- Confident that your doctors know what is happening inside your body.
- Glad that your parents and doctors are helping you stay healthy.
- Happy that you are still the same special person that you always have been.

You may also have other feelings that are not on this list. No matter how you feel now, it's okay. All of your feelings are normal, and it is okay to have them. VHL may seem scary, but it does not have to be. You are not alone, and you are not the only kid who has VHL. Most kids with VHL have healthy and happy lives. It may help to talk to other kids who have VHL, and Chapter 10 will give you information on how you can communicate with them.

CHAPTER 9: SHOULD I TELL PEOPLE THAT I HAVE VHL?

Should I tell people that I have VHL?

People with VHL do not look any different than people without VHL. No one will be able to look at you and know that you have it. The only way people will know that you have VHL is if you decide to tell them. You may feel that you do not want anyone to know, and that is okay. You may decide to only tell a few people, and you may decide not to tell anyone. It is all up to you.

Right after you find out that you have VHL, you may not feel like talking about it. It may be hard to talk about, even with people whom you are very close to. That is okay and completely normal. If you do talk about it eventually, you will feel better. First, talk to your parents or someone you are close to. Later, you may decide to tell your friends. Your parents can help you decide which friends to tell, how to tell them, and when to tell them. Perhaps you would only like to tell your close friends, the kids you trust, and the kids that care about you.

Will my friends treat me differently because I have VHL?

A true friend will not treat you differently because you have VHL. True friends will know that you are still the same person you always have been. VHL does not define who you are, it does not make you different. You will always be a special person whether you have VHL or not.

CHAPTER 10: CAN I TALK TO OTHER KIDS WHO HAVE VHL?

Where can I find kids who have VHL?

Since VHL is rare, it may seem hard to find other kids who have VHL, but believe it or not, there are kids all over the world who have it! A great way to find and communicate with other kids who have VHL is through the internet (with your parents' permission).

If you visit the VHL.org website, you can find support resources for kids of all ages, including helpful information at: www.vhl.org/kids. You can also connect with other kids with VHL who understand the feelings you have, through our Penpal Program. You never know, you may meet lots of new friends!

Who else can I talk to for help?

If you ever need to talk to anyone, do not be afraid to talk to your parents. Your parents can even make an appointment for you to talk to a counselor. As we mentioned in Chapter 7, counselors understand people's feelings very well, and it is their job to help you in any way they can.

Remember, there is always someone who is there for you. If you or your family ever need more advice or support, you can always contact the VHL Alliance at (800) 767-4845 or visit www.VHL.org.

CHAPTER 11: WILL THERE EVER BE A CURE FOR VHL?

A cure for VHL?

Right now, there is not a cure for VHL. Scientists and researchers are studying VHL and other diseases to help prevent them or control them. Medical science is learning more and more about DNA and gene therapy. It may be possible that one day doctors could replace or fix our mutated VHL *gene* with a normal, working gene.

There is good news though! In 2021, a medication became available for adults with VHL to help stop tumors from growing. Although this pill is not meant for kids with VHL yet, you might be able to take it when you are older to help prevent tumors.

Is there anything I can do to help find a cure for VHL?

Yes! You can help raise awareness of VHL, which means telling a lot of people what VHL is. Since it is rare, there are many people that have never even heard of it. You can also create, contribute to, or help fundraisers for VHLA – the VHL Alliance. Encourage your family members who have VHL to join an available clinical trial so doctors and researchers can learn more about new treatments.

Can kids my age help too?

Yes! Kids your age may be the ones to find a cure for VHL! So, keep up your studies in school and encourage your friends to remember that education is very important, not only to them, but to everyone. Your friends can help you to raise awareness, and the more we learn about VHL, the faster we can find a cure together!

WORD GLOSSARY LIST

50% (fifty percent): A 50% chance is one chance out of two possible outcomes, like a coin toss. If you flip a coin, there are only two ways it could land: heads or tails. Each time you flip a coin, there is a 50% chance of it landing heads up.

Adrenal glands: These glands are located on top of each kidney (most people have two). They help control hormones, or chemical messengers, that send signals from one cell to another. People with VHL may get tumors called pheochromocytomas in the adrenal gland.

Audiologist: An audiologist is an ear doctor who gives hearing exams (audiograms) to determine hearing loss and function.

Blood test: A test where a doctor or a nurse will take a sample of a person's blood using a needle. The test doesn't hurt much if you relax, some people say it feels like a poke in the arm.

Brain: The brain is located in the head: it is the body's main control center for the nervous system. The brain controls bodily functions. It also controls thought and reason. People with VHL may develop tumors in the brain.

Cancer: Cancer happens when healthy cells do not grow in an orderly manner. Cancerous tumors are called malignant tumors. Malignant tumors can destroy healthy cells that are near the tumor and possibly spread to other parts of the body.

Cells: A cell is the smallest unit, or building block, of all people and living things. Each cell has a special job to do like being a brain cell or kidney cell. Every cell in a person's body contains DNA and genes, which have a set of instructions to tell the cells what to do. A person is estimated to have 100 trillion cells in their body.

Cheek swab: A cheek swab is taken with a small swab by rubbing on the inside of a person's cheek in order to pick up cheek cells that contain DNA. The DNA is used for genetic testing.

Clinical trial: A clinical trial is the study of people with certain diseases by doctors and researchers. Doctors perform different tests or give different medications to people in a clinical trial in order to see if the tests or medications make their health better. This is how doctors and researchers can potentially find cures, medications, or treatments to prevent and control disease.

Counselor: A professional person (psychological expert) who helps people of all ages deal and cope with disease, difficulties in life, stress, and more. A counselor is a person who talks with people alone or with their families based on their situations or needs.

Cyst: A cyst is a collection of fluid or liquid. Cysts in the abdomen usually do not cause symptoms or physical problems. Organs usually function normally with them.

DNA: DNA stands for deoxyribonucleic acid. DNA is found in every cell of the human body. DNA contains genes, which provide instructions for how our cells work. Every person gets half their genes from one parent and half from the other.

Ears: The ears are organs of hearing, which allow us to listen to sound. The ears also play a role in balance. People with VHL may get tumors in their inner ear.

Eyes: The eyes are organs of sight, which allow you to see and detect light. People with VHL may get tumors in their retina (See 'Retina' below).

Gene Mutation: A change in the sequence, or instructions, of a gene; there are many different mutations that can occur. Sometimes a mutation is never discovered, sometimes a mutation causes a cell to stop behaving normally, and sometimes it may cause a disease, such as VHL.

Gene Therapy: Gene therapy is a technology that is still being explored and learned about by doctors, scientists, and researchers. The idea of gene therapy is to replace or repair genes that are not working properly so that they work the way they are supposed to.

Genes: Genes are found in every cell of the body on long curly ladders of DNA. Genes carry directions on how cells should work. They are the blueprint for how our bodies function. Every person has two copies of every gene in each cell, one copy from each parent. It is estimated that every person has over 35,000 genes in their body!

Genetic Counselor: A professional person (medical genetics expert) who helps patients and families cope with genetic diseases. The counselor also gives information to patients and helps them find doctors who can help treat them.

Genetic Testing: A test that looks at the genes within a person and finds gene mutations. The test is usually performed in a laboratory with a blood sample or cells from a cheek swab.

Hereditary: When genes are passed on from a parent to their child. Certain characteristics, such as hair color or eye color, are hereditary, as well as certain diseases, like VHL.

Kidneys: The kidneys are located in the abdomen and most people have two. Kidneys are organs that filter blood and get rid of waste products by turning them into urine. People with VHL may get tumors in their kidneys.

Laboratory: A laboratory, also called a lab, is where lab technicians, doctors, researchers, and scientists work. A lab is a place where research and experiments are performed. In medical labs, blood and urine may be tested in order to get health information about a patient.

MRI: MRI stands for Magnetic Resonance Imaging. This is a machine that takes pictures of the inside of a person's body. The machine uses magnetic energy, so no radiation is used. The pictures appear on a computer screen. The MRI machine can take pictures of soft tissue (like kidneys) or hard tissue (like bones).

Operation: See the definition for surgery.

Ophthalmologist: An eye doctor who specializes in diseases and surgery of the eye.

Ophthalmoscope: A magnifying lens used by an eye doctor to examine the eyes. This tool can be used to see the health of the retina.

Pancreas: The pancreas is a gland organ that is located behind the stomach. It aids in the digestion of food. People with VHL might get tumors in their pancreas.

Pheochromocytomas: A tumor of the adrenal gland, which is called a "phéo" for short. Pheos can sometimes be found in other areas outside of the adrenal glands.

Researchers: There are many different types of professional researchers who study many different things. They investigate, discover, learn, and share their knowledge with others.

Retina: The retina is a small membrane that covers the inside of the back part of the eye and allows us to see. The optic nerve sends these images to the brain. People with VHL may get tumors in the retina. A retinal specialist is a doctor who specializes in treating the retina.

Scientists: There are many different types of professional scientists. Scientists study many different things like the body, animals, nature, outer space, and more! Scientists perform tests or experiments in order to learn more about the thing they are studying.

Screenings: Screenings are tests that a doctor orders to monitor what is going on inside of your body. In VHL patients, there are recommended screenings based on your age. Most people with VHL have these screenings done once a year, but this depends on the person and their family history.

Spine: The spine is located in your back. Sometimes it is referred to as your backbone. The spine is made up of small bones called vertebrae that hold up your back and protect your spinal cord, which contains many nerves.

Spinal Cord: The spinal cord is a bundle of nerves that run from your brain down through the holes in the vertebrae of your spine. It carries signals between your brain and other parts of your body. People with VHL may get tumors in their spinal cord.

Surgeon: A doctor who performs operations. There are many different types of surgeons. Surgeons specialize in the treatment of different parts of the body.

Surgery: One way that doctors can remove tumors, treat injuries, or improve how the body works is by performing surgery. There are many different types of surgeries. In general, surgery, or operation, is done in a hospital while the person is asleep. Most people need time to recover from surgery. The time needed to feel better is different for each person and based on their health and the type of surgery they had.

Symptom: A symptom is a feeling or sensation that makes you feel differently than you normally feel. Sometimes a symptom may be a pain or weakness in a certain part of the body. If a symptom does not go away, you should be examined by a doctor in order to figure out what the cause is.

Trait: A trait is a feature or characteristic such as blue eyes or brown hair. Genes are responsible for our traits.

Tumors: A tumor is a collection of cells that do not behave like normal cells anymore. Tumors can be benign (non-cancerous) or malignant (cancerous).

Ultrasound: An ultrasound machine uses sonar by bouncing sound waves off the parts of the inside of the body to create images of specific organs. The doctor or nurse will rub a probe with jelly over the part of the body that needs to be checked. The pictures appear on a computer screen. There is no radiation with ultrasounds.

Urine Test (24-Hour): A test used to check for levels of catecholamines and metanephrines, which are hormones or chemicals, found in the urine. Urine is collected for a 24-hour period in a special jug that is kept in the refrigerator. After the test is done, it needs to be taken to the laboratory to be examined.

Von Hippel-Lindau: A rare, hereditary disease that may cause tumor growth in various parts of the body. The disease is named after two doctors who first found it: Dr. Eugen von Hippel from Germany and Dr. Arvid Lindau from Sweden.

VHL: VHL stands for von Hippel-Lindau and is used when talking about VHL disease

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VHL Kids' Handbook



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