



# DFS

and



# Living My Best!



# A NOTE TO PARENTS AND GUARDIANS

Welcome to “LFS and Living My Best!” This booklet supports information about Li-Fraumeni syndrome (LFS) that you and the health care team have shared with your child. It is aimed at children ages 8 to 13 years.

Each child and each family is different. This booklet may have details that you or the health care providers have not shared with your child yet. Please review this booklet before passing it along to your child to see if the information is right for your child at this time. Your child might like reading this booklet with you, an older sibling, or another adult. That way your child can ask questions and have you explain things. Your genetic counselor, doctor, or other health care provider can help with questions you or this booklet are unable to answer.

We hope “LFS and Living My Best!” is helpful for you and your child.

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ASSOCIATION  
GENETIC COUNSELING ADVISORY GROUP



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# WHAT IS LFS?

LFS stands for Li-Fraumeni syndrome. It is named after the doctors who discovered the syndrome: Dr. Frederick Li and Dr. Joseph Fraumeni. Li-Fraumeni syndrome is a lot to say, so most people just call it LFS.



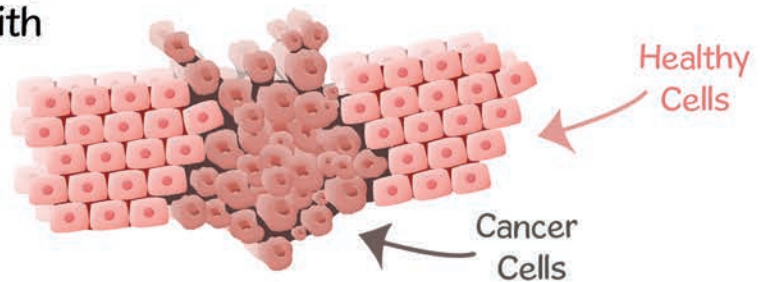
Dr. Frederick Li

Dr. Joseph Fraumeni

Anyone can have LFS. People with LFS do not look different than people who don't have LFS. Even doctors can't tell who has LFS by looking at them. LFS has been found in families all over the world. People with LFS are born with a greater chance of getting cancer.

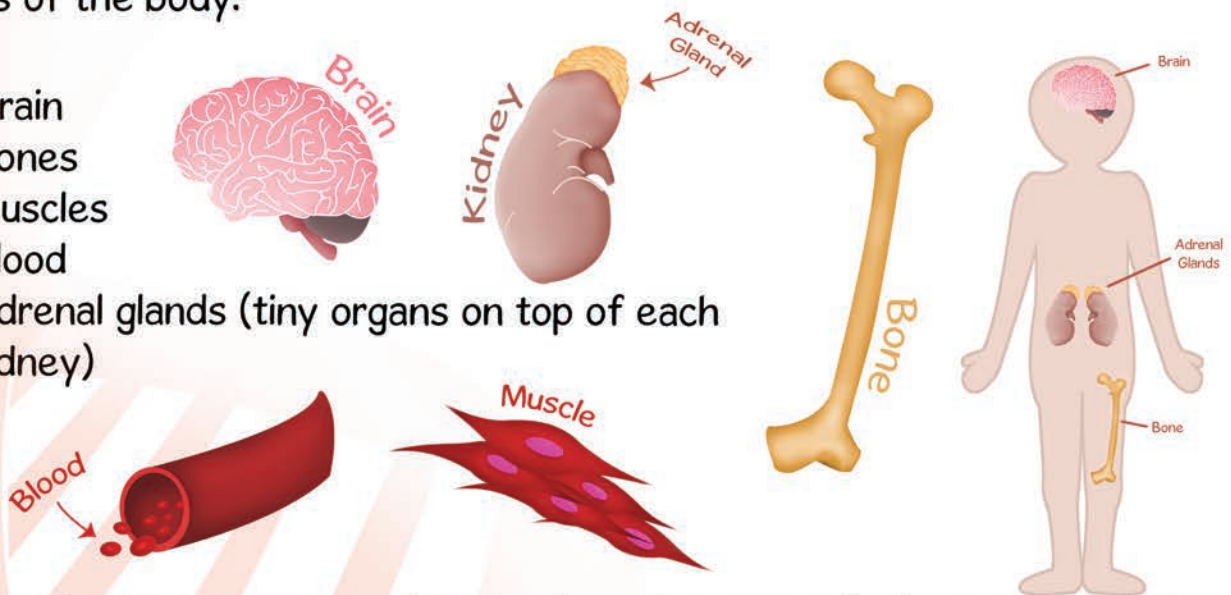
# WHAT IS CANCER AND WHAT DOES IT HAVE TO DO WITH LFS?

Cells are the building blocks of our bodies. Cancer can happen when the signals that control cell growth don't work properly. Cancer cells keep growing and multiplying when they should stop. They can spread to parts of the body where they do not belong and make people sick. Cancer can often be cured if it is found as early as possible. The risk of getting cancer increases for all people as they get older. However, people with LFS have a greater chance of getting cancer than people without LFS. Many people with LFS don't get cancer in childhood and some people with LFS never get cancer at all.



It is possible for people with LFS to get just about any type of cancer. However, certain types are more common in childhood, especially in these parts of the body:

- Brain
- Bones
- Muscles
- Blood
- Adrenal glands (tiny organs on top of each kidney)



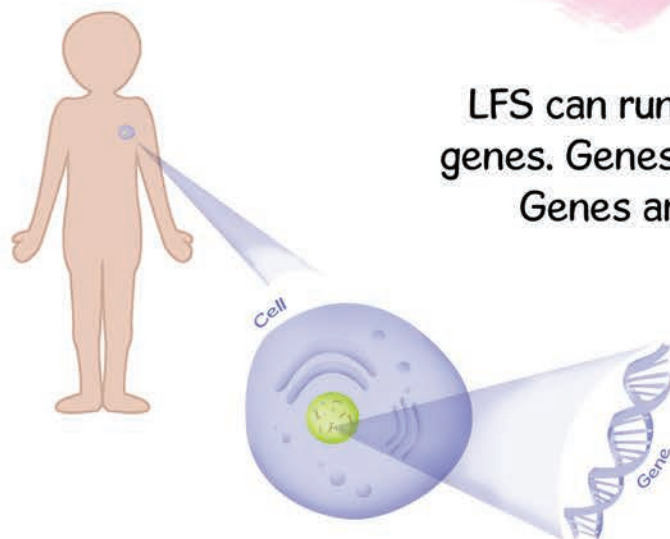
Adults also have a greater chance of getting cancer in these parts of the body. Adult women also have a greater chance of getting breast cancer.



# DOES ANYONE ELSE IN MY FAMILY HAVE LFS?

LFS runs in families. Many children with LFS have a parent with LFS. Other people in your family may have LFS, like brothers, sisters, grandparents, aunts, uncles, or cousins.

Sometimes a person with LFS is the first one in the family to have it. If you are the first person in your family with LFS, your parents, brothers, and sisters do not have it, but your future children might.

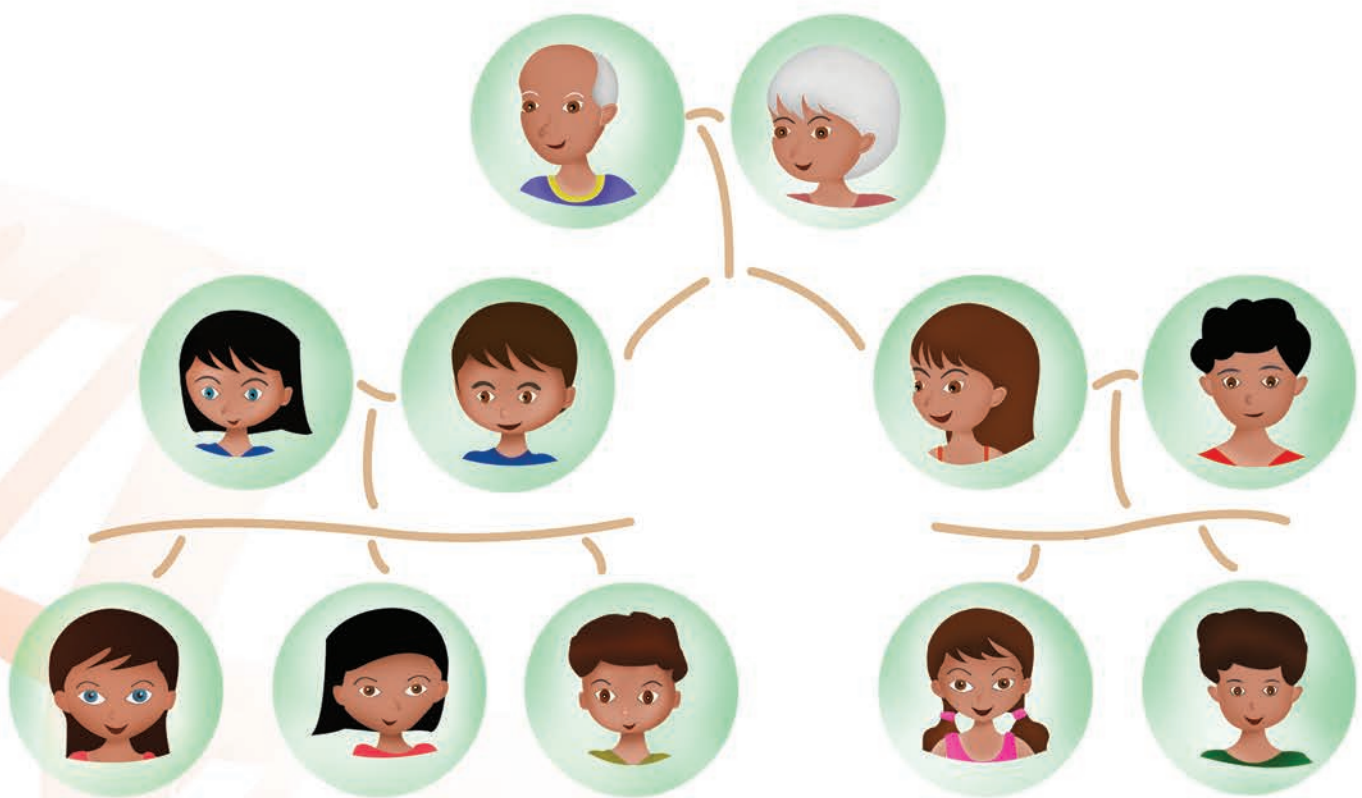


LFS can run in a family because families share genes. Genes are found in the cells of our body. Genes are like recipes for making a person. They tell the body how to work.

We usually think about genes related to how we look, like genes for eye color or hair color. Someone may have told you certain things about you—like your smile or the shape of your nose—make you look like one of your parents. This is because we get our genes from our parents. Some genes also protect us from getting cancer.

Changes in genes, also called variants, can cause health problems. People with LFS are born with a change in a gene that normally protects people from getting cancer. This change makes the gene stop working the way it should. That's what causes LFS.

If one of your parents has LFS, you have a chance of getting LFS, too. Your chance of having LFS is the same as your chance of not having LFS. This is called a 50% chance, or 1 chance in 2. It is like the chance of a coin landing heads-up or tails-up when you flip it. This chance is the same for every child in the family. In some families, all the children will get LFS. In others, none of the children will get LFS. Many times, some of the children will have LFS and some won't.



Once in a while, more than one child in a family has LFS even when the parents do not. If your family is like this, a genetic counselor can help explain why. Whether you have LFS or not, you still share with your family members many other genes that have nothing to do with cancer.



## HOW DO I KNOW IF I HAVE LFS?

A genetic test is the best way to find out whether or not you have LFS. A genetic test looks for a change in the gene for LFS. This gene is called *TP53* (sometimes called p53).

There are reasons you might have the test and reasons you might not. Each family makes their own choice about whether to do the test and when might be the right time to do it. Usually, someone else in your family with LFS has the test first. If you have cancer, you may be the first person in the family to be tested for LFS.



## What will the test tell me?

You might find out you have LFS. Having LFS does not mean you have cancer. It does mean you will need regular check-ups with a doctor to look for early cancer signs.

You may find out you do not have LFS. If you do not have the gene change that causes LFS in your family, you will never get LFS. Your risk for getting cancer will usually be the same as other people without LFS.



## HOW IS GENETIC TESTING DONE?

The genetic test is usually done by taking a small blood sample. Some people are scared of this because it is done with a needle, but it doesn't hurt much. Most people say it feels like a pinch on the arm. You may have had a blood test before and know exactly what it feels like. Sometimes it is possible to do the genetic test using saliva (spit) or a cheek swab—done by gently scraping the inside of the cheeks in your mouth.



It may take several weeks to get the answer from the genetic test. It is OK to feel nervous about having a genetic test. You should talk about any worries with an adult you trust, like your mom or dad or a genetic counselor.

## WHAT IS CANCER SCREENING?

If you have LFS, you will need check-ups with the doctor and cancer screening. Cancer screening means looking for cancer before a person has any cancer signs. There is no way to prevent cancer from happening in a person with LFS, but not everybody with LFS will get cancer. Cancer can often be cured when it is found early and treated right away. Many different types of cancer can happen in people with LFS. So, it is important to do screening in many different parts of the body.

Doctors check for cancer by doing regular screening. This may include check-ups, blood tests, and using machines such as ultrasounds and MRIs.

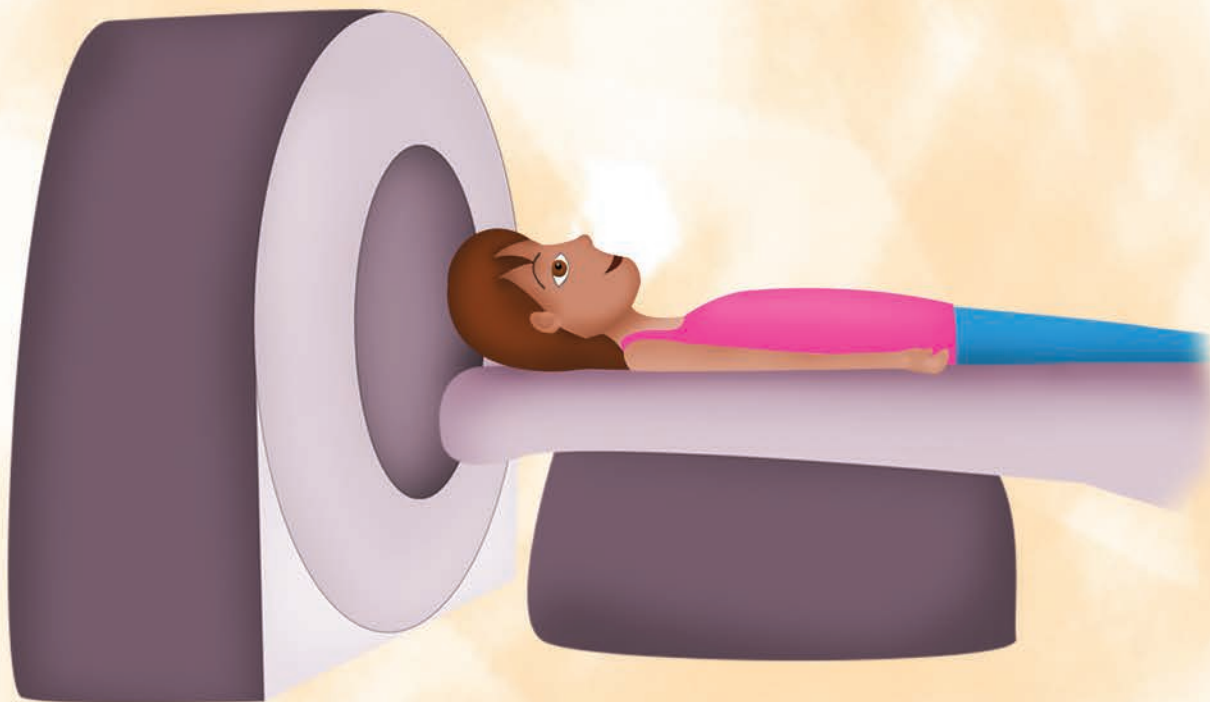


The ultrasound machine uses sound waves to take pictures of what is inside your body. A technician puts a gel, kind of like a jelly you don't eat, on the part of the body the doctors want to view. The technician moves a special camera around in the gel to take pictures of what is inside you.



The MRI machine is a large tube you lie down inside. A technician helps from nearby as the machine uses magnets to take pictures of the inside of your body. Nothing touches you while you are in the MRI machine.

MRI Machine

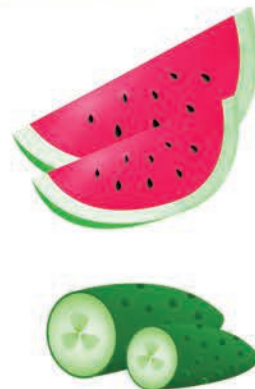


The ultrasound and MRI machines do not hurt, but you do need to lie still to make sure the pictures are clear enough to look for and find cancer if it is there. Screening with the MRI usually takes about 45 to 60 minutes. If this is too long for you to lie still, it is possible for the doctors to give you medicine to help you relax or even fall asleep during this screening.

# WHAT CAN I DO TO LOWER MY CHANCE OF GETTING CANCER?

While there is no way to stop cancer from happening in a person with LFS, there are things that people can do to lower their chance of getting cancer. These include:

- Eating a healthy diet with lots of fruits and vegetables
- Getting regular exercise, like playing sports, walking, or swimming
- Being careful about how much time is spent in the sun and always wearing sunscreen and protective clothing (long sleeves and hat) when out in the sun
- Avoiding smoking (cigarettes, cigars)
- Avoiding spending time with people who are smoking (secondhand smoke)
- Avoiding radiation when possible. Radiation is a type of energy harmful to the body's cells. It is used to treat some types of cancer and also is used in many different machines.



Adult women with LFS can also talk with their doctors about what can be done to lower their chance of getting breast cancer.



# WHAT SHOULD I WATCH FOR IN MY BODY?

People with LFS should watch closely for cancer signs, such as:

- Unexplained weight loss
- Loss of appetite—not feeling hungry or not wanting to eat when you normally would
- Aches, pains, lumps, or bruises that cannot be explained
- Headaches or changes in eyesight (vision)
- New moles or changes in moles or other areas of skin

If you have any of these signs, you should tell your parents and your doctor.



# WHAT DO I DO IF I HAVE CANCER?

If the doctors find you have cancer, they will do everything they can to get rid of the cancer and keep you healthy. Your cancer might be treated with any or all of the following:

- Surgery
- Chemotherapy (cancer-fighting medicines)
- Radiation therapy (a type of treatment that uses radiation energy)

Sometimes cancer treatment may cause you to feel sick. It is important to let your parents and doctors know how you are feeling.



You should know you did nothing wrong to cause the cancer. Cancer cannot be passed from one person to another. It is not possible for someone to “catch” cancer from you.

It is OK to feel worried or sad if you have cancer. You should talk about your feelings with an adult you trust, like a parent, doctor, or genetic counselor.



## WHAT DOES LFS MEAN FOR MY LIFE?

You might already know you have LFS. You may not like having LFS. You may know that other people in your family with LFS had cancer. Although many people with LFS do get cancer, LFS can be different in everyone who has it—even in members of the same family. You may never get the type of cancer other people in the family had. It is possible that you may never get cancer at all. It is important to remember that people with LFS can live long, healthy lives.



Sometimes, children with LFS worry other people will treat them differently. Remember, your friends and others will not know you have LFS unless you tell them. Children who have LFS do not look different. You might have met someone who has LFS, and you did not know it.

For many children, learning they have LFS does not change much about their lives. Every child is different and can have different feelings about having LFS. No matter how you feel, it is OK. You may have different feelings about having LFS at different times in your life. Sometimes you may feel:

- Like you are different than other children.
- That LFS is no big deal.
- Tired of talking about LFS.
- That having LFS is not fair!
- Lonely, because you have LFS and others don't.
- That you have a special connection with other family members who also have LFS.
- Confused. "What are they talking about?"
- Sad.
- Scared.
- Worried about different aspects of having LFS.
- Tired of going to doctors' visits.
- Worried about a family member who is sick from LFS.
- Happy that knowing about LFS will help your doctor keep you healthy.



Many people who have LFS are happy and healthy. Sometimes, it can help to know other children who have LFS. You are not alone. There are lots of children who have LFS.



## SHOULD I TELL OTHERS I HAVE LFS?

When you first find out you have LFS, you might find it is hard to talk about it. You may feel nervous when you talk about it, even with your parents. This is completely normal, but it will help you feel better if you ask questions and share your feelings. Your parents can also set up a time for you to talk with a doctor or a genetic counselor who is used to talking to children and adults about LFS.

If you want, you can tell some of your friends about LFS. Talk to your parents first. They will help you decide who you should tell and what you should tell them. No one can see that you have LFS by looking at you. However, if you miss school for doctors' visits, you may want some of your friends to know the reason.



You'll find you will usually feel better after you talk to family members and friends you trust and who care about you.

# HOW CAN I CONTACT OTHER CHILDREN WITH LFS?

You might be the only one at your school or in your town who has LFS. Sometimes this can feel lonely. But there are lots of other children who have LFS! More than anyone else, they know what it's like to have LFS and what it feels like to think you are the only one.



One way to get in touch with other children with LFS is through support groups. After talking about it with your parents, you can learn more about the groups listed below by sending them an email or finding them on the Internet. Many libraries and schools have Internet access for people who don't have it at home.



# The Li-Fraumeni Syndrome Association

The Li-Fraumeni Syndrome Association (LFSA) is an advocacy group active on Facebook, Twitter, Instagram at **/lfsassociation** and online at **LFSAssociation.org**. The LFSA also has a private Facebook Group, Voices of LFS, at **/groups/573233369849062/**.

You can contact the LFSA by email at **info@lfsassociation.org** or by phone at **1-833-4MYLFS** (1-833-469-5372).

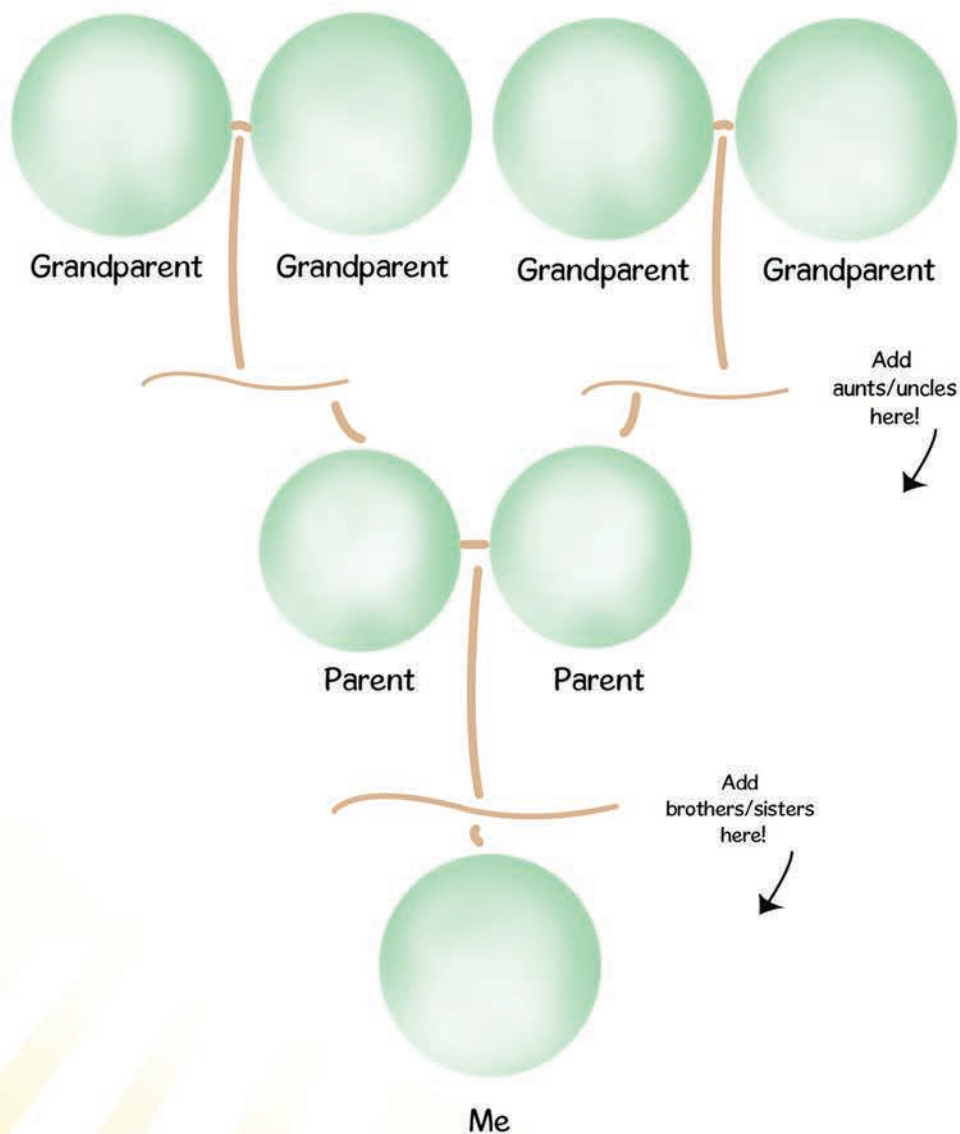


The LFSA Youth Program provides support to teens and young adults with LFS (ages 13-25) by connecting other LFS youths from around the world and providing learning opportunities from experts in the field in fun and engaging ways such as Youth Workshops, webinars, and quarterly Youth Newsletters. Learn more at **LFSAssociation.org/youth-program/**.

The LFSA has international chapters in Africa, Australia/New Zealand, Canada, France, Germany, India, Japan, Latin America, Netherlands, Saudi Arabia and Singapore. Learn more by visiting **LFSAssociation.org**.

# MY FAMILY TREE

Now it's your turn to draw your family tree! Draw pictures of your family members and put their names underneath. You can do what you want in the circles: draw or print pictures, write names, or write or draw something about your family members. Families come in all shapes and sizes, so feel free to change labels, add in anyone who you think is special in your family, or make your own tree to make a drawing that works for your family. If you don't know who a family member is, you can put in a "?". If a family member has passed away, you can draw or write something special to remember them by.





# WORD SEARCH!

Circle all the words you can find in the word search below. All the words you can find are listed below. Words can go forward, backwards, downward and diagonally.

T D R L M I X Z V S U R Y G V  
B W L L F N I A R B O S N W C  
X E U H R F U Y P N K I V O Q  
C B D U U D A B N W M E I M H  
W A L K I N G M R M G G U E A  
D Y S K T A A Y I E Y S H N E  
X O Y N S M I W T L C B X E S  
L B O N E M S A A L Y O C G I  
F A X L R E B C E A K N H U C  
F V L I B L R H D G R F Q B R  
L N C D E P I C W M Q Y B Y E  
G F O S D N U O S A R T L U X  
E X S P X D K H O N E M S R E  
Z U V V S W C M L B U R R Q O  
E J D K U D E M I P R S O Q I

LFS  
gene  
DNA  
cell  
family  
sunscreen  
exercise  
fruits  
vegetables  
walking  
swimming  
MRI  
ultrasound  
muscle  
brain  
bone  
blood

## RESOURCES FOR PARENTS

Li-Fraumeni Syndrome Association  
[www.lfsassociation.org](http://www.lfsassociation.org)  
1-833-4MYLFSA (1-833-469-5372)

Medline Plus: Li-Fraumeni Syndrome  
(<https://medlineplus.gov/genetics/condition/li-fraumeni-syndrome/>)

Cancer.net: Li-Fraumeni Syndrome  
[www.cancer.net/cancer-types/li-fraumeni-syndrome](http://www.cancer.net/cancer-types/li-fraumeni-syndrome)

Children's book for ages 4–7 years:  
Peasgood, A. & Peasgood, R. Robot Music: A Story for Kids with  
Li-Fraumeni Syndrome and Other Cancer Predispositions. Tellwell Talent.  
2019.





## WORD LIST

**Cancer:** cells that grow fast and can spread to parts of the body where they do not belong. Cancer cells make people sick. Cancer can often be cured if it is found early and treated right away.

**Cells:** the building blocks of your body. Cells are the smallest living parts of you. Many different kinds of cells make up your whole body—skin cells, brain cells, blood cells, and others.

**Chemotherapy:** medicines that help fight cancer.

**Genes:** instructions that tell your body how to work.

**Genetic counselor:** a person with special training for talking to parents and children about LFS or other genetic conditions.

**Li-Fraumeni syndrome (LFS):** a genetic condition that makes a person more likely to get cancer.

**MRI:** a large machine with a tube you lie inside while the machine looks inside the body. It uses magnets to make the pictures. It does not use radiation.

**Radiation:** a type of energy harmful to the cells of the body. It is used to treat some types of cancer and is also used in many different machines.

**TP53:** an important gene that protects the body from getting cancer.

**Ultrasound:** a machine that uses a small, handheld camera to look for cancer inside the body.

**Variant (also known as “mutation”):** a change in a gene that might cause health problems.

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