

Paving the Road: A RUNX1 Communication Guide for Parents



National Institutes of Health
Turning Discovery Into Health

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How This Guide Can Support Your Conversation

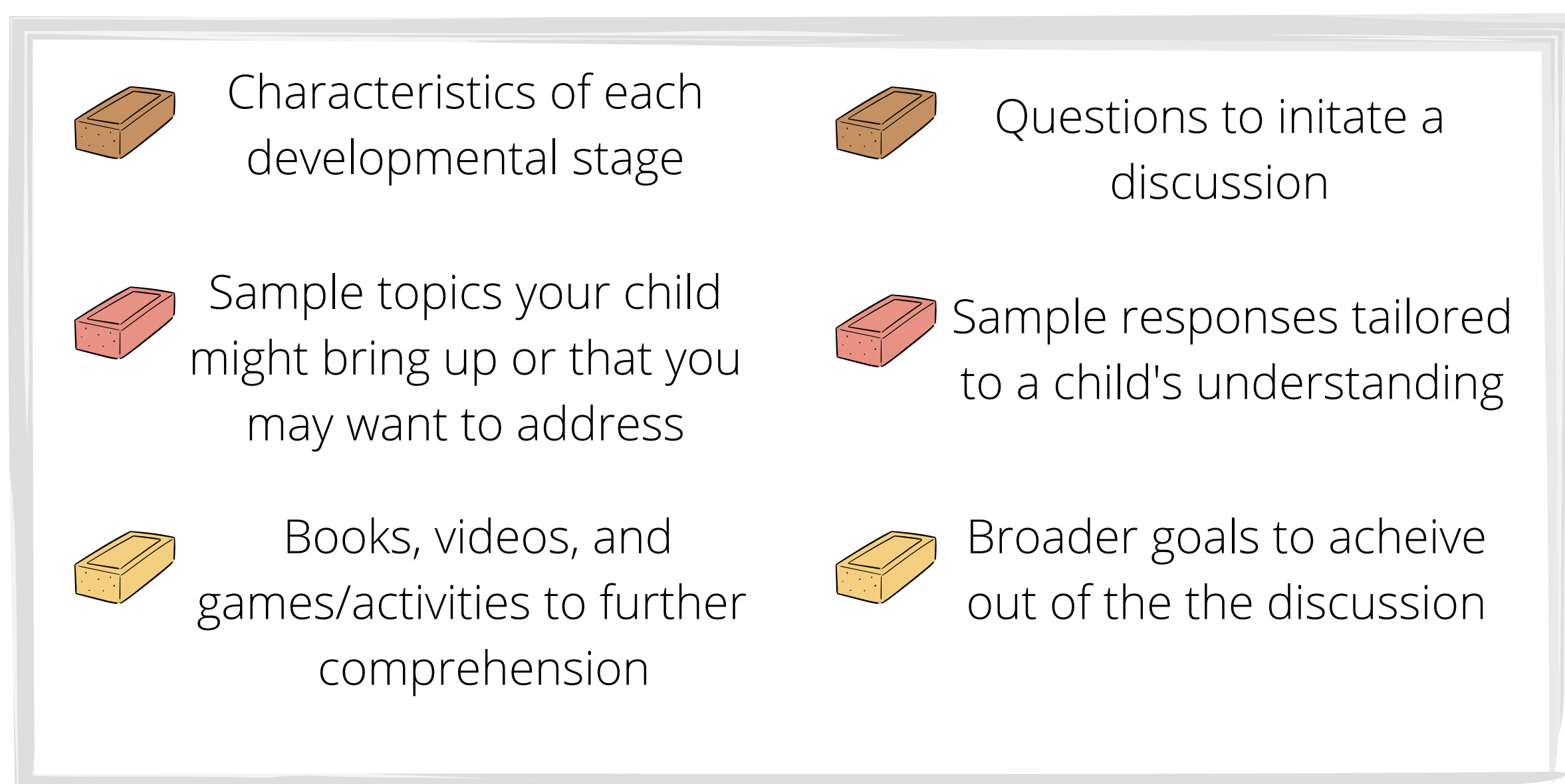


When RUNX1 variants are diagnosed in the family, many parents express uncertainty about when and how to communicate with their child(ren) about the condition. While you may feel like you need to address everything all at once, it can be helpful to think about these conversations like paving a brick road. You don't have to complete the road all at once. Build the road slowly, one brick at a time.

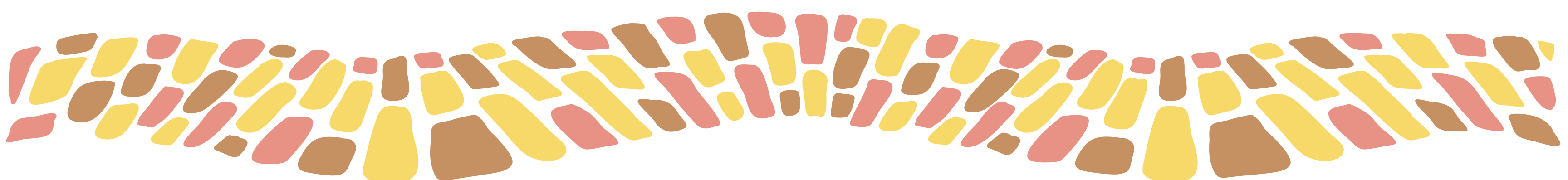
In an early conversation with your child, introduce a topic related to RUNX1 that you can build on later, such as what blood cells are. By doing this, you've laid down your first brick and that might be plenty of information for the initial conversation. The next time you speak to your child, you can revisit that brick and build upon it. You might start out the next conversation by asking, "Remember when we talked about blood cells?" As your child forms the connection, you can then continue the conversation by adding a new topic. For example, "Dr. X and Dr. Z are blood cell doctors we see to keep a close eye on our blood cells. Our blood cells are different, and they help make sure we are safe and healthy." By adding small amounts of information at a time, tailored to your child's development, you pave a stronger, smoother road for your child to tread. Once a road is paved, you can travel it more comfortably when new information is available or needs to be shared.

This guide is designed to help you build your road by providing some starting bricks that may help you approach conversations about RUNX1 and support your child's understanding. This guide will meet you where you are today. Your child may have already come to you with questions about RUNX1, or you may be wondering how to bring up the diagnosis for the first time. This will provide language you may use to talk about genes, gene changes, genetic testing, cancer risk, and other relevant topics with your child. The suggested conversations are not designed to be a script, but rather to be tailored to your child and family. The content is based on the authors' collective clinical experience. We provide considerations for children of different developmental ages, from preschool age to high school.

Throughout this guide, you will find:



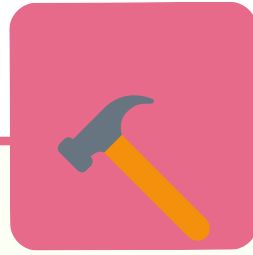
Note that this isn't a rigid template, but rather a guide. You know your child best, and you may find resources and additional guides to better fit your child's needs.



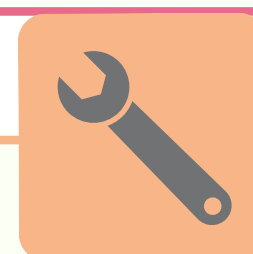
A foundational 'toolbox' of concepts to consider before the conversation



When and Where

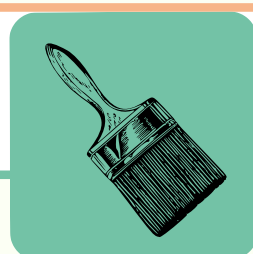


- Start communicating with your child early; children often hear more than we think, and open conversations will help ensure accuracy of information.
- Consider what time of day will allow for a more focused conversation.
- Choose a quiet, private, familiar location.



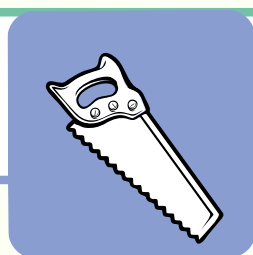
Assess Understanding

- You can start with open-ended questions such as how they are feeling or
- what they have heard already about RUNX1.
- Provide honest information in small digestible pieces so that your child can have time to process.
- Summarize what you've discussed at the end/



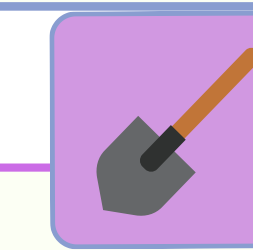
Listen to Questions

- Leave room for your child's questions and try to answer them directly.
- If you do not know the answers, let them know that honestly.
- Keep open communication with your child around doctors' appointments, and try to simplify medical words used.



Know the Learning Style

- Consider including a second caregiver, counselor, or healthcare provider in the conversation.
- How does your child learn best? Use additional resources based on whether they prefer to learn by seeing, hearing, or doing.
- Ask them if they are ready to talk about more serious issues.



Steps Ahead

- Follow up individually with siblings to include them.
- Keep communication consistent and ongoing.
- Update your healthcare team about the conversations you've been having with your child.
- Address concepts with your healthcare team, such as physical activity, genetic testing, social media resources, and mental health/coping.

A focus on feelings: at this age you can start to help your child express their emotions and to normalize sadness

General Conversation Starters:

How was your day?

Is there anything you want to talk about?

How are you feeling?

Tips for Approaching Conversations:

- Reinforce and validate feelings
- Reassure child to not feel shame about any part of their identity/medical condition
- Identify yourself as a trusted adult to talk to about worries or concerns
- Initiate discussions about areas that could be a concern

Your child may ask...

Why do I bleed/bruise more than my friends?

Our bodies have many ways of responding when we get hurt. Sometimes, when you get hurt, your skin turns more purple or bleeds, sometimes more than other people. You do need to tell an adult when you get hurt so we can take care of you.

Why do I have to go to the doctor so much?

Everybody's body works a little bit differently. Just like other people in our family, your body tends to bleed and bruise more easily. This isn't something to be worried about, but we do have to be a little bit more careful.

Additional Resources:

Examples of Books:

The Color Monster Goes to School

Mouse Was Mad

Talk and Work It Out

Lots of Feelings

My Many Colored Days

Games/Activities (Linked)

Coloring Worksheet by Sources of Strength
What Makes You You? What Makes Me Me?

Extract Your Own DNA

DIY Edible Candy DNA

Nature or Nurture Quiz (for older Elementary/Early Middle School)

Wear a Chimp on Your Wrist: Arts and Crafts Activities for children with cancer By UHN

A focus on awareness: at this age you can start to talk about genes, medical conditions, going to the doctor, cancer, and what it means to be healthy

Your child may ask...

What are genes?

Genes are our body's instructions for how we look and grow. Everyone's genes are a little bit different. Genes are made up of DNA which is really just a code (like letters in a book) that spell out the instructions. Sometimes when we get a spelling error in our genes and DNA it can lead to medical conditions.

Are these medical conditions scary? Are they contagious?

Just like we share things like how we look (sometimes called traits) we also share things about our health. In our family we have a condition called RUNX1. Going to the doctor and having our blood checked can help us stay healthy. And, unlike the flu, genetic medical conditions like RUNX1 stay within the family, so you cannot give them to your friends.

What is RUNX1?

Having RUNX1 means that some members of our family might bruise or bleed a little bit more easily than other people. We need to visit the blood doctor more often to make sure we stay as healthy as possible. Your body just works a little bit differently, and that's OK.

Whose fault is it that you/I/we have RUNX1?

Having RUNX1 isn't anyone's fault. Spelling errors in our genes happen at random and sometimes, they can get passed down without our control.

What is cancer?

Cancer causes some cells – the teeny tiny building blocks of our body – to not work correctly and they can grow out of control. The unhealthy cells can keep growing and forming more unhealthy cells that can spread in our body and cause sickness. It is important to get rid of those unhealthy cells to protect our good cells. There are certain medicines that are used to get rid of the unhealthy cells.

Tips for Approaching Conversations:

- Empower children to have a role to play in their care (ex. picking their bandaid, choosing which physical activities are comfortable to pursue...)
- Normalize going to the doctor
- Follow conversation up with pictures and games
- Encourage their follow-up questions and curiosity: don't make them feel guilty for speaking their mind

Additional Resources:

Examples of Books:

The One and Only Me
Things That Make Me Special
You Share Genes With Me
How Do You Care for a Very Sick Bear?
Cancer Hates Kisses
It's Time for Your Checkup

Games/Activities (Linked)

[Coloring Worksheet by Sources of Strength](#)
[What Makes You You? What Makes Me Me?](#)
[Extract Your Own DNA](#)
[DIY Edible Candy DNA](#)
[Nature or Nurture Quiz \(for older Elementary/Early Middle School\)](#)
[Wear a Chimp on Your Wrist: Arts and Crafts](#)
[Activities for children with cancer](#) By UHN

A focus on content: at this age you can start to talk about DNA, inheritance, mutations

Your child may ask...

What is RUNX1? How did we get it?

RUNX1 is a gene that is important for helping our blood cells grow correctly. The RUNX1 variant in our DNA happened by chance, and it means that we have some problems with the way our blood develops, causing some people in our family to bleed/bruise more easily. It also makes us a little bit more at risk for certain blood cancers. Since we know about our RUNX1 variant, we can work with our doctors to make sure we stay as healthy as possible.

Is RUNX1 contagious?

No, it's not. While RUNX1 gets passed through our family, this happens before a person is born, and you cannot pass it on to other people who are not in the family, like your friends in school.

What are genetic variants/mutations?

Genetic variants (sometimes called mutations) are “spelling changes” in a person’s DNA. They can lead to changes in our body. Sometimes these genes can lead to small changes (like making us like or hate cilantro or helping us roll our tongue). Sometimes variants make us healthier, but then sometimes if changes happen in the wrong genes they can lead to medical conditions. These variants get passed on through families. RUNX1 is just one of many genetic variants that get passed on through our family.

What is genetic testing?

Since our genes are written out in letters (DNA) scientists can actually use genetic testing to run spell check on our genes. This lets them see if a person might have a spelling change in a gene like RUNX1 which could lead to issues in your health.

In the media, I've seen that some people with cancer don't have hair. Why?**

People with cancer can lose their hair when they take chemotherapy (a special, strong medicine to destroy the unhealthy cells in their body). Because some of these medicines are so powerful, they can also harm good, fast growing cells, like hair cells, causing hair to fall out.

Tips for Approaching Conversations:

- Introduce more complicated concepts
- Give them time to fully process information and connect them to genetic counselors/healthcare providers to address confusion or worries
- Integrate wellness and coping strategies for stress

Additional Resources:

Examples of Books:

Gene Mutations: Causes and Effects
Chill and Spill: A Place to Put it Down and Work it Out

Videos/Activities (Linked)

[Heredity: Crash Course Biology #9](#)
[TED-Ed: How Does Chemotherapy Work?](#)
[Genetics Riddles: Tour of Mendel Park](#)
[DNA Detective: Crack the DNA Code](#)

**See “elementary school” section for starting a conversation about cancer

A focus on complexity and consequences: at this age you can start to talk more deeply about RUNX1 specifically and the effect of medical conditions on social relationships.

Your child may ask...

What is RUNX1?

The RUNX1 gene produces blood cells from stem cells. However, when there is a spelling error in the gene it disrupts these functions, can cause people to have a low platelet count, which means more bleeding and bruising. People with spelling errors in RUNX1 are also more likely to develop certain types of blood cancer so they need to go to the doctor more frequently to try to prevent cancer or catch it early if they do get it.

How should I talk to friends about this?

It's totally up to you. Just make sure you let them know that a genetic variant doesn't definitely mean you'll develop cancer. Also let them know that a doctor is guiding you so you take the needed steps to prevent cancer.

What does my RUNX1 mean for my future family?

If you have the RUNX1 variant and end up having children there is a 50-50 or 1 in 2 chance that you could pass it on to your children. If you decide to have children a genetic counselor can help you talk through these risks and different options for having children.

I don't want you to reveal this to my teacher/counselor/other adult

I know how you feel about it being personal, but it can be helpful for them to know about this so that they can support you if needed. Having said that, it is up to you about who you tell about this and how you talk to them. I'm here to support you however you need it. If you would like me to talk to them, I'm happy to do that as well. There are also many other social media groups if you want to openly communicate with people you can relate to.

Tips for Approaching Conversations:

- Introduce more complicated concepts
- Give them time to fully process information and connect them to genetic counselors/healthcare providers to address confusion or worries
- Integrate wellness and coping strategies for stress

Additional Resources:

Text:

CDC Summary of Genetic Testing

Chill and Spill: A Place to Put it Down and Work it Out

Videos:

(Netflix) *Cells at Work*

TED-Ed: How Does Chemotherapy Work?

RUNX1 Research Program Video

Hematopoiesis Khan Academy

Games/Activities:

Interactive Lessons about Cancer

Genetics Riddles: Tour of Mendel Park

DNA Detective: Crack the DNA Code

Extract Your Own DNA

Social Media Groups:

Official RUNX1-FPD Facebook

Genetic Alliance Facebook



A reference of words that may come up in conversation along with definitions that are easy to understand for children

DNA

Molecule that carries genetic instructions in living things

DNA is really just a code. We think of DNA as being written out in letters (A, T, C, and G) and just like any code it can sometimes have typos or spelling errors. When we do genetic testing we are basically just running spell check on the genes to look for typos.

Gene

Segment of DNA and unit of heredity that codes for RNA or protein

Genes are our body's instruction manual or cookbook that tells us everything we need to function and grow. They get turned on at different points in our life and they make these things called proteins. Protein is just the word scientists use to describe all of the material that forms most of your body. There are many different proteins that each have a unique function - they make our muscles move, our hair grow, and our eyes a certain color.

Heredity

Passing on characteristics coded for by DNA from parent to child

People might say that you look like different people in your family. That's because we share lots of different characteristics with our family members, like the way we look. These characteristics are coded for in our genes and are passed down through generations. While we can share lots of cool things with our family members, like our eye color, hair color, or height, that means we can also share things like genetic medical conditions (such as RUNX1). This phenomenon is called heredity, and a trait is heritable when it can be passed on to family members.

Cell

The basic structural, functional, and biological unit of all known organisms

Super tiny parts of the body that fit together like Legos to build us. We have cells in our skin, our bones, our hair....everywhere! Our cells grow all the time and we are always making new cells.

RUNX1 (the gene)

A gene that produces blood cells from stem cells

A gene that is the recipe for making our blood cells work correctly. When there is a spelling error in a person's RUNX1 gene it means that their blood doesn't always work correctly, which can cause them to get sick.

RUNX1 (the condition)

Hereditary condition caused by an error in the RUNX1 gene. Also written as RUNX1-Familial Platelet Disorder (RUNX1-FPD)

A condition that runs in our family and is caused by a change in our DNA. It's the reason why some people in our family bruise and bleed more than other people and why sometimes we have to go to the doctor a bit more often for checkups.

Genetic Variance (Mutations)

DNA changes that can lead to altered expression of the RUNX1 gene

"Spelling changes" in DNA that lead genes to be different. Sometimes spelling changes are good and help create new words, but sometimes when your body can't read the word correctly it can lead to medical conditions, like RUNX1.

Platelets

Blood cells that help clotting and stopping bleeding

These are cells in your blood that act like teeny tiny band aids. Just like when we put a band aid on a cut to stop you from bleeding on the outside, your platelets stick together in your blood so your body can stop the bleeding from the inside.

Thrombocytopenia

Low platelet count

If there aren't enough platelets in your blood it can take a little bit longer for your body to form its internal band aid and you may bleed for a little bit longer than other people.

Aminocaproic acid (Amicar)

Prescription medication to help control bleeding when the blood doesn't clot the way it should

This is our way of giving your body some extra bandaids when we know it might need them to help you heal.

Cancer

A disease in which abnormal cells divide uncontrollably and make it harder for the normal cells to do their job. It may also spread to other areas of the body.

Treatment includes chemotherapy and radiation.

Some cells, the building blocks of our body, stop working properly and become bad. These bad cells keep growing and forming more teams of bad cells that can spread in our body and cause sickness.

Leukemia

A cancer of white blood cells that affects the blood and bone marrow and hinders ability to fight infection. For acute cases, treatment includes chemotherapy, sometimes followed by radiation and stem-cell transplant

White blood cells are like soldiers that battle invading infections. When you have Leukemia, your bone marrow creates white blood cells that have changes to them, so these cells are like injured soldiers who can't fight the infection and protect the body anymore.

Chemotherapy (Chemo)

Treatment that destroys cancer cells with drugs

A medicine that kills bad cells in the body and stops cancer. Sometimes it can accidentally kill some of our good cells which can make us feel sicker, but this means that the medicine is doing its job.

Radiation Therapy

Treatment of a disease, including cancer, using X-ray radiation

During radiation therapy, powerful x-rays will be aimed at specific parts of your body like light sabers to help get rid of enemy cancer cells. Radiation therapy is a lot like getting an x-ray.

Genetic Testing

Analyzing cells for changes in genes that may be a sign of a condition (such as RUNX1 variant)

Your genes are made up of thousands and thousands of letters, just like words in a book. Genetic testing is like running a spell check to look for typos that can tell us if you might have a particular medical condition, like RUNX1.

Bone Marrow

Soft sponge-like material found inside bones

Your bone marrow is the factory that makes all of your blood cells and your immune system. It is home to thousands and thousands of special cells called stem cells. Your bone marrow is soft and spongy and is protected by the hard outside of your bones.

Bone Marrow Aspiration and/or Biopsy

a procedure to examine the bone marrow and give detailed information on the health of the blood cells.

This test that helps us check how healthy your blood cells are. It is very important to keep you healthy. During this test the doctor will take a little bit of your bone marrow. Your doctors will give you medicine to help keep you comfortable during the test and you may even be asleep. It is normal to feel sore after the test. There is medicine that you can take by mouth to make you feel more comfortable.

Hematopoietic Stem Cells

“Shape-shifter” cells in bone marrow that develop into different kinds of blood cells (such as white blood cells, red blood cells, and platelets). Hematopoietic just means blood.

Baby cells that start out their life in the bone marrow factory. As they grow up, they'll turn into your red blood cells, white blood cells, and platelets. As the cells grow, they'll move into your body's bloodstream (the highway cells use to get around) so they can move around and do all the things blood needs to do. Some of your stem cells also keep turning into new stem cells so you always have cells on deck to become whatever type of blood cell you may need. RUNX1 is important for helping our stem cells turn into other types of blood cells like platelets.

Stem Cell Transplant

When healthy bone marrow cells (stem cells) are transplanted into a person who has diseased or damaged marrow.

A stem cell transplant is when we take healthy bone marrow from another person to help replace damaged cells that aren't doing their job correctly. Because we are transplanting the whole factory, once a person gets a bone marrow transplant their body can keep making new cells as it needs them.



Your NIH RUNX1 Team

.....> > > >

(You can fill in the blanks with the names of your specialists)

Hematologist – a doctor specializing in blood diseases

Nurse – performs physical exams, performs medical interventions per prescriber direction, provides education and support

Research Nurse - Organizes patient care activities, coordinates treatment, collaborates with other members of health care team, obtains study protocol consent, and guide patients to better understand their health status and needs

Nurse Practitioner or Physician Assistant – Advanced practice provider that assesses patient needs, interprets diagnostic and laboratory tests, diagnoses disease, and prescribes treatments.

Genetic Counselor – healthcare professionals that use family history to assess individual/family risk of a heritable condition (like RUNX1)

Patient Care Coordinator - Helps patient to organize their travel, lodging, and scheduling needs



Other Specialists You May Meet

Pulmonologist – a doctor specializing in the respiratory system (breathing and oxygen flow)

Allergist – a doctor specializing in allergies

Gastroenterologist – a doctor specializing in stomach and intestinal disorders

Dermatologist – a doctor specializing in skin disorders

Gynecologist – a doctor specializing in female reproductive health

Oncologist – a doctor specializing in tumors and cancer

Neurologist - a doctor specializing in brain and nervous system disorders

Rheumatologist - a doctor specializing in musculoskeletal and autoimmune conditions like arthritis

Social Worker – a health professional who assists and supports children and families, including in coping with illness

Pain specialists – health care professionals who specialize in acute and chronic pain



This guide has provided many different ways to communicate to your child(ren) about RUNX1. Sometimes, in an attempt to protect a child from difficult information, parents avoid talking about issues that can become problematic at a later date, like needing more medical care in the future. Although this is done with the best intentions, it can lead to unintended consequences including your child having even more worries based on misinformation.

With this guide as a helping hand, you can start putting down some bricks that may help you approach conversations about RUNX1. With each conversation about a new topic, you will pave a road for future conversations. Your child's understanding will increase over time and your relationship will build as well.

This information is prepared specifically for persons taking part in clinical research at the National Institutes of Health Clinical Center and may not apply to patients elsewhere. If you have questions about the information presented here, talk to a member of your health care team.

Products/resources named serve as examples and do not imply endorsement by NIH. The fact that a certain product/resource is not named does not imply that such product/resource is unsatisfactory.

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