



My EB Doctor Visit!

My Name: _____

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EB CLINIC

- At the clinic, different doctors work together to make sure I get all the help I need for my skin and help me feel my best.
- Lots of doctors and other helpers will come in to see me. I can ask for a break or tell my grown-up how I am feeling if I get overwhelmed.
- It is ok (and actually great!) to ask questions.
- There are times my grown-up will ask me to talk or just listen, and when I take my time and feel ready, I can do that. I can play quietly too!



My ideas of fun things to do:

DOCTOR'S OFFICE

- I visit the doctor to make sure I get all the help I need for my body and to help me feel my best.
- Doctors, nurses and other helpers may come in to see me. I can ask for a break or tell my grown-up how I am feeling if I get overwhelmed.
- It is ok (and actually great!) to ask questions.
- There are times my grown-up will ask me to talk or just listen, and when I take my time and feel ready, I can do that. I can play quietly too!



My ideas of fun things to do:

DERMATOLOGY

Date & Time: _____

With Doctor: _____

My doctor and the team will come to talk to us about my skin and the biggest problems I'm having with blistering.



We will unwrap a few places, and the doctor will examine my skin gently. We can tell people not to touch me without asking.

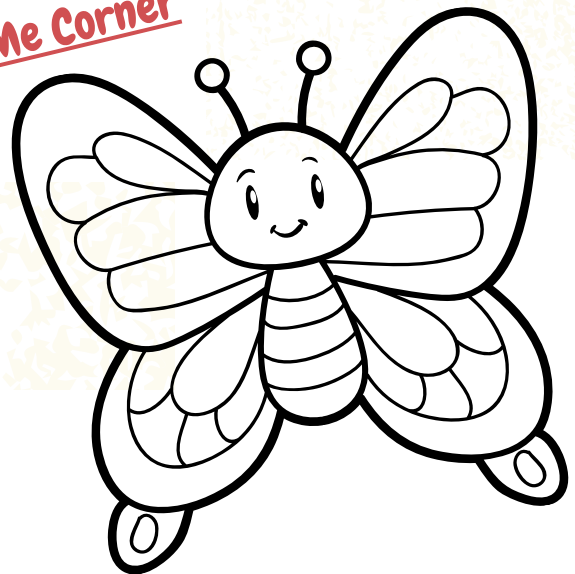
We will talk about how to take care of my skin every day, and ways to help heal my sores.

After that, my grown-up will re-do my bandages. I can _____ and then we're done!

Add your questions here:



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DEXA SCAN

Date & Time: _____ with the Dexa Team!

A DEXA scan is sort of like an x-ray to look at my skeleton and bones. It can tell how strong they are.

A camera will move over my body to look at my whole skeleton.



I will lay still on a table and it will move around a little.

Nothing will touch me and nothing will hurt. It's all pretty quick!

Add your questions here:

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EYE DOCTOR-OPHTHALMOLOGY

Date & Time: _____

With Doctor: _____

Ophthalmology is the study of eyes and vision.

The eye doctor will look at my eyes with different tools. No touching.

At the eye doctor, we will check my vision and how well I can see.

We will talk about if my eyes ever hurt me, and what we can do to help my eyes.



Add your questions here:



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GI (GASTROENTEROLOGY)

Date & Time: _____

With Doctor: _____

GI is a short way to say “gastroenterology” which is a fancy word for the system of your esophagus, stomach, and colon.



We will talk about any tummy troubles I have, and the doctor will help.

The doctor may ask how well I can swallow and chew my food, or if I have a special tube to help me get nutrients.

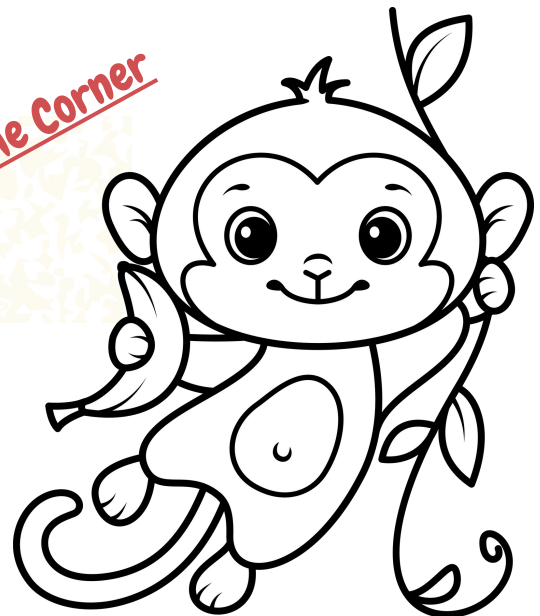


They may want to listen to my belly or feel it gently with their hands. It should not hurt.

Add your questions here:



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HEART TEST - ECHO

Date & Time: _____ with the Heart Team!

A camera is used to look at my heart and make sure it's nice and strong.

The camera touches the gel on my skin and slides easily. It doesn't hurt.

They will put some gel on my chest to prepare for the pictures, gently pulling down any bandages I have on.



No tape and no stickies!! They will take pictures of my heart. I will stay still and can _____ while I wait.

Add your questions here:

Color Me Corner



HEART TEST - EKG

Date & Time: _____

With Doctor: _____

An EKG checks how my heart is beating. Little stickers need to be applied to my chest. But my grown-up and nurses know how to keep my skin safe.

I can tell my grown-up if something doesn't feel good and they will help. Wires will be clipped to the stickers, not my skin.

The stickers are carefully placed to make sure they are in the right spots and my bandages may need to be pulled down.



I will stay very still so they can see how my heart is beating. Then we'll take off the wires and the stickers, and it's done!

Add your questions here:



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HEART - CARDIOLOGY

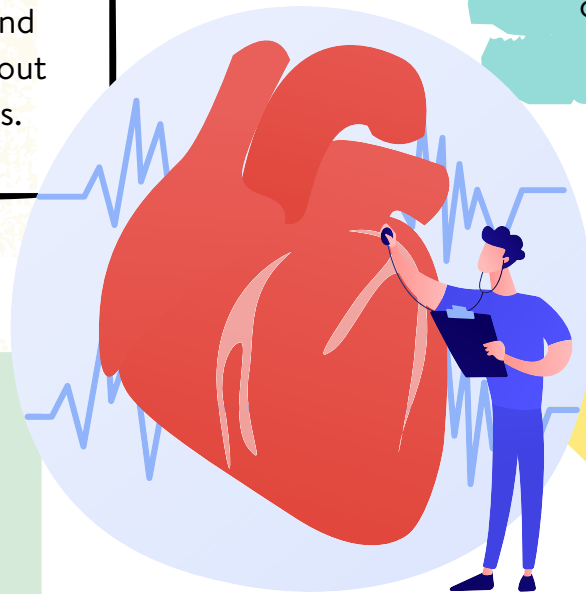
Date & Time: _____

With Doctor: _____

We will meet with the doctor after the heart tests, and they will talk with us about the results of the tests.

I can ask questions about my heart, the tests I did, or anything else!

The doctor may want to listen to my heart and lungs, with a stethoscope.

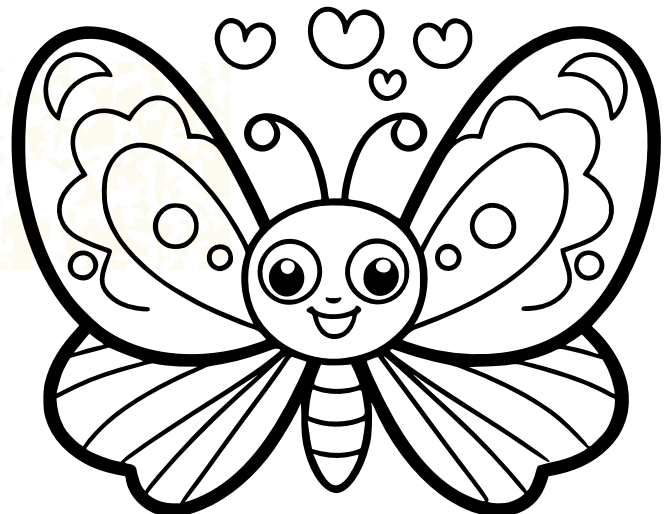


I can talk or stay quiet, or I can bring a toy if I am feeling nervous. It's up to me!

Add your questions here:



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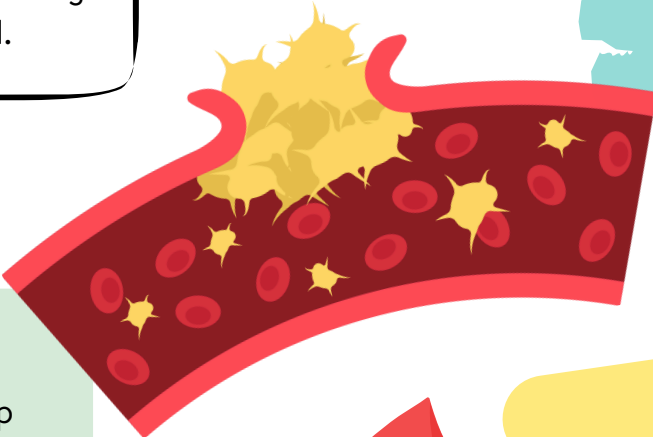
HEMATOLOGY

Date & Time: _____

With Doctor: _____

Hematologists are doctors who study blood and help kids feel strong and energized.

Just talking - no touching!



Hematologists help people with EB in lots of ways, including making sure I have enough iron in my body.

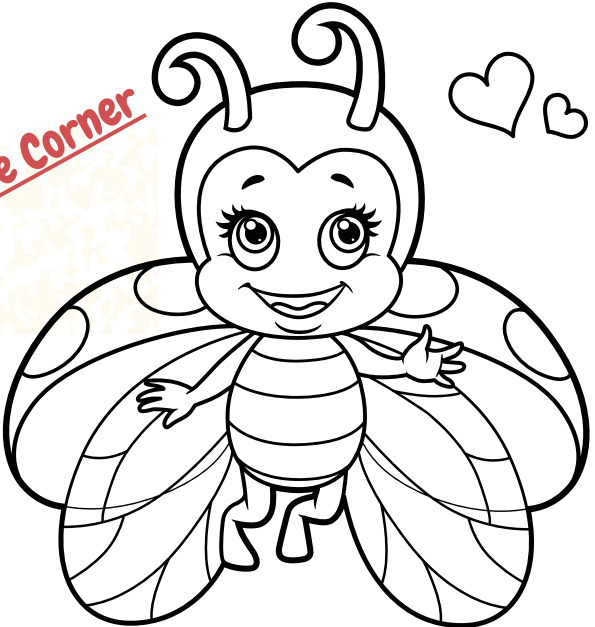
We will talk about bleeding, medicines, how great I am doing. I can talk or use a distraction.



Add your questions here:



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NEUROLOGY

Date & Time: _____ With Doctor: _____

My doctor will help my brain and nerves work their best.

We will definitely talk about my unique, smart brain.

We may talk about medications, anxiety, and more.

They're like brain detectives, solving puzzles to help me feel better! They will give me tools to succeed.

Add your questions here:

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NUTRITION

Date & Time: _____ With: _____

Here, we get to talk about all kinds of foods and snacks that make me feel strong and happy!

We will also talk about what hurts my mouth, throat or tummy, and ways to make me feel better.

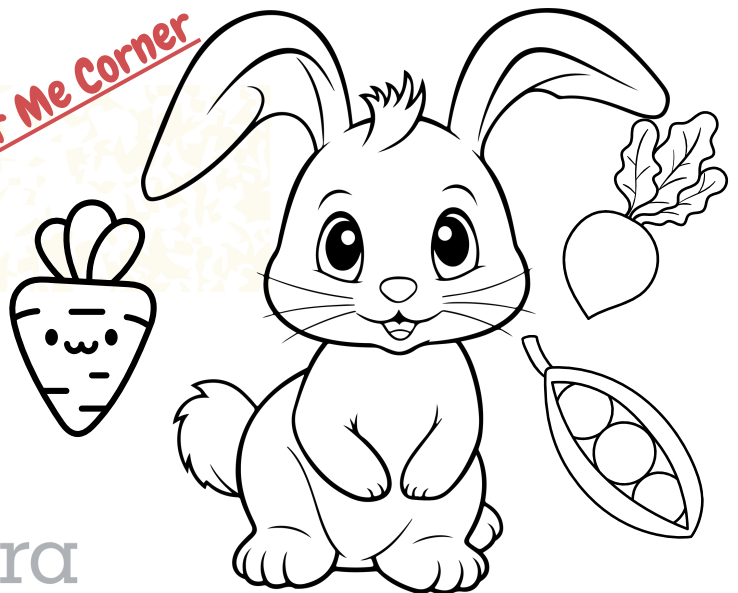
Good nutrition is what helps me grow and stay strong.



It's important I am a part of this conversation, because only I know how my body feels.

Add your questions here:

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OCCUPATIONAL THERAPY

Date & Time: _____ With: _____

During OT, we will play fun games and do exercises that help me stay strong and active.

I may learn about special tools or gadgets that make activities like eating or writing easier and less painful.

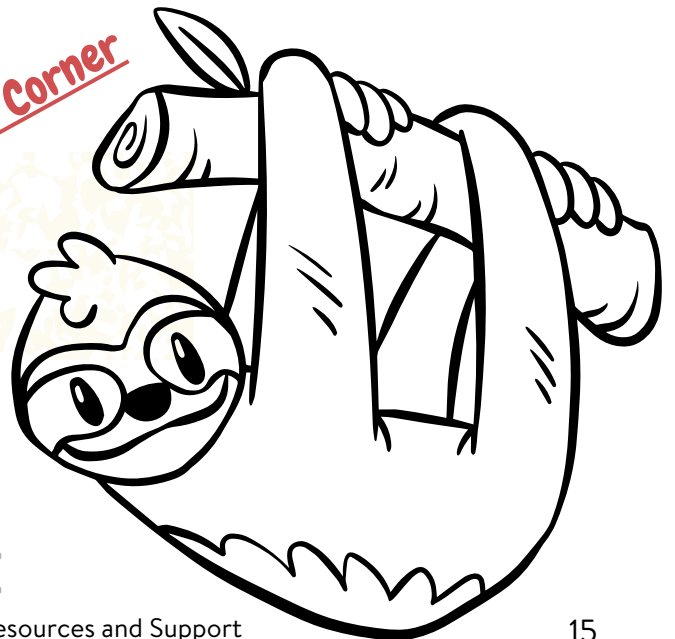
I can show them how well I can use my hands and how I move around.



I can be excited to learn how to take care of myself and try new things on my own!

Add your questions here:

Color Me Corner



ORTHOPEDICS - FEET

Date & Time: _____

With Doctor: _____

My foot doctor knows a lot about kids' feet and ways to keep them happy.

We may show them my feet, and run and jump right in the office.

We will talk about feet and any pain I feel. We may also talk about shoes, stretching and exercises.



This is a great time for me to talk about when my feet hurt, or when I may get tired or feel discomfort.

Add your questions here:



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ORTHOPEDEICS - HANDS

Date & Time: _____ With Doctor: _____

My hand doctor is a hand expert! They will ask to see my hands and gently check how they move.

We may talk about wrapping my hands and keeping them strong.

They may show me fun games and stretches, or even special tools like splints or soft grips.

With my hand doctor's help, I become a hand expert, knowing exactly how to take care of my hands and keep them high-fiving.



Add your questions here:

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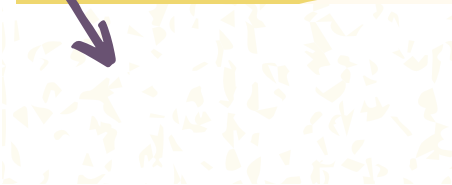
PAIN & ITCH DOCTOR

Date & Time: _____ With Doctor: _____

My doctor will come to talk about pain and itch.

I can talk about where I feel pain and how much.

Add your questions here:



We can tell people not to touch me without asking.

I can choose when to talk, or when to take a break.
I can also:

Color Me Corner



PALLIATIVE CARE

Date & Time: _____ With Doctor: _____

The “Good Life” Team are doctors, nurses, and helpers who want to help me have a good, fun life.

This team also talks to my other doctors and helps everyone work together.



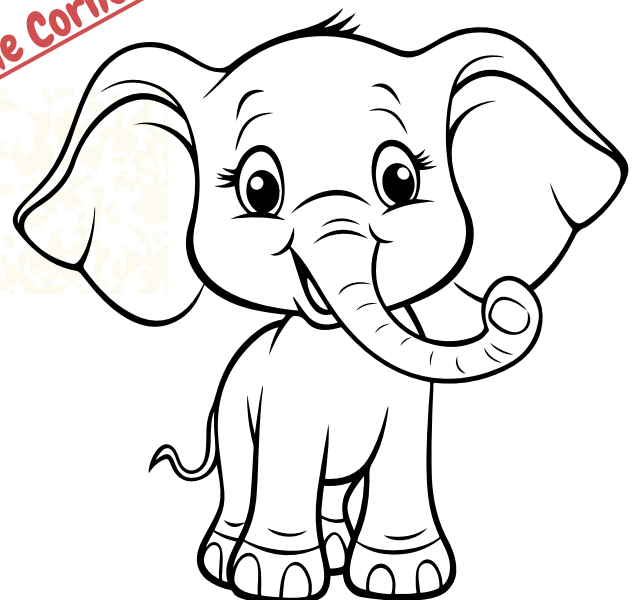
We will talk about what I love and what is fun for me. And how awesome I am!

We may talk about what is hard for me, as well as things I do to help me with pain.

Add your questions here:



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PHYSICAL THERAPY

Date & Time: _____ With: _____

During PT, we will do fun exercises that will help me walk, run, or jump better.

We will practice new ways to move my body.



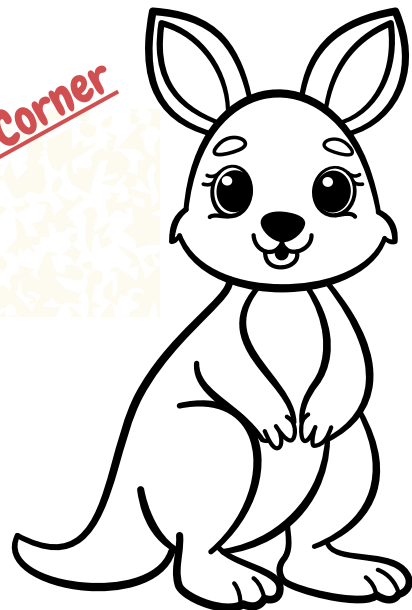
I can show my PT what I do with my body, like run, jump, balance, and move my arms and legs.

I may get to play a few games, and my grown-up may ask some questions. I can ask questions too!

Add your questions here:



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PSYCHIATRY

Date & Time: _____ With Doctor: _____

Psychiatrists help kids with EB who may feel sad, worried, or scared sometimes.

They may suggest ways to feel better, like taking medicine and talking about our feelings.

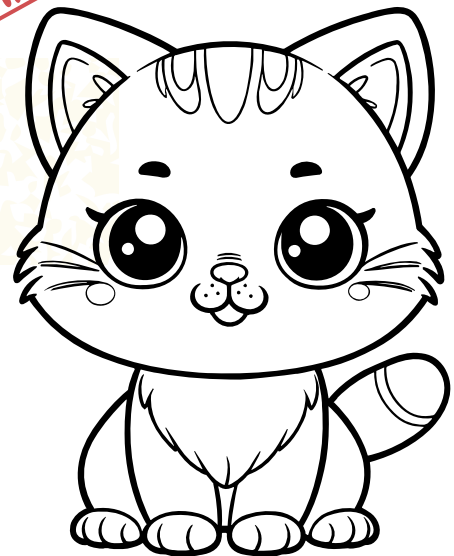
Just talking!
No touching.

I can ask any questions I have or say anything I'd like about how my brain works. I am the expert!



Add your questions here:

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PSYCHOLOGY

Date & Time: _____

With: _____

I get to share all about my thoughts and feelings during this time, and my doctor listens carefully.

We can talk about things I am awesome at, my independence, and if I want to, anything that makes me sad.

Psychology is a fancy word to talk about how you feel and emotions.

I will learn how to become my own superhero, handling tricky situations and feeling good about myself!

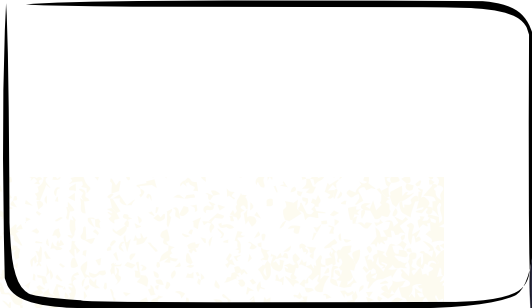
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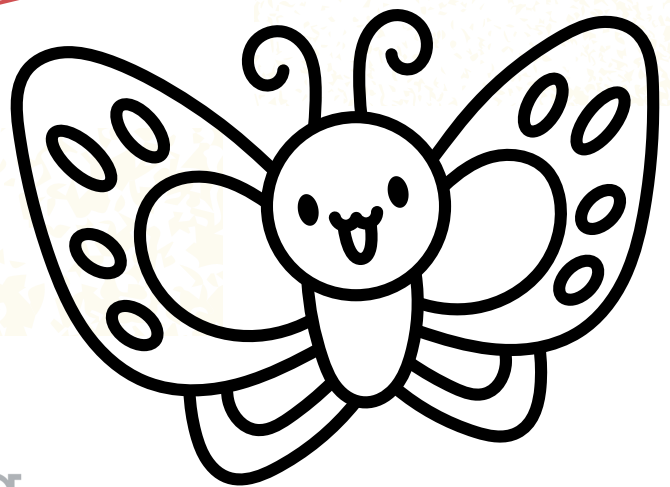
MY DOCTOR'S VISIT

Date & Time: _____ With Doctor: _____

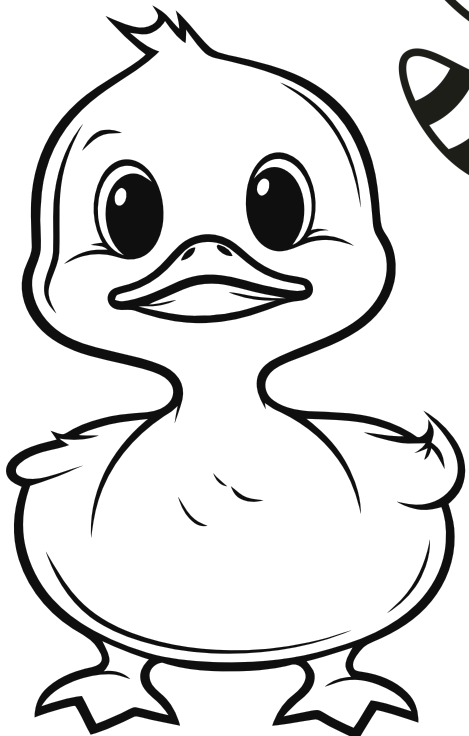


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Add your questions here:



MORE COLORING FUN



ACKNOWLEDGEMENT

Special thanks to Laura Dellicker, MSW, LCSW, for writing this social story to support children with EB in navigating doctor visits and EB clinic appointments.

