ALBERT IS LIKE ME!

Sample copy. Not for use without institutional review board or ethics committee approval.
Message to parents:

You have made the decision for your child to participate in the 111-206 study. We know that being a part of a clinical trial may be a new experience for you and your child. The purpose of this book is to help you, as a parent or caregiver, explain to your child what to expect during the study. Using simple language, pictures and activities, we hope to lower fears and help your child prepare for the study.

This is only a general overview of the study. Please refer to the Informed Consent Form and speak with the study doctor about the risks of participating in the 111-206 study.
Hello!
My name is Albert.
I am taking part in something special for kids like us.
My doctor tells me kids like us are taking part from lots of places. Follow me to learn more!
My bones, like your bones, are growing in a different way from other kids’ bones.

Doctors want to see if a new medicine might help our bones grow better. They also want to make sure the medicine is okay for us to take.

To see if the new medicine works and is okay for you, you will see the doctor and nurse a lot.

Sometimes you will be at the hospital the whole day. You might even have a sleepover at the hospital.

I like to bring my favorite toy with me — Bunny. Sometimes I bring puzzles and coloring books. Do you have things you want to bring with you?
When you see your doctor and nurse, they will look at lots of things. They will check how tall you are and how much you weigh.

They will take pictures of your bones with a big camera. The pictures show how your bones are growing. I think the camera is kind of cool!

Another machine is used to look at your heart. That one is much smaller and looks like an octopus.

Your nurse will want to take some of your blood. At first, I was really scared of the needle.

My nurse was really nice and she put something cold on my arm. I did not feel too much – just a little sting. My daddy says I am really brave. Mommy thinks so, too.
The new medicine is given as a shot. My friend Annie says it looks like a little rocket.

The shot is given at home every day. My mom and dad are really good at making it quick. Blink and it is over! Your mom and dad will make it quick too. And they will give you a big hug when it is done.

The medicine has to be given in a different spot every day. I tell mommy if I get any red bumps from the shot or if I do not feel good.

Can you name the different spots on me where the medicine can be given?
I know all the nurses and doctors now. They are my new friends. I do not even need mommy’s and daddy’s help finding all the rooms anymore. My mom and dad and my doctor are really proud of how brave I have been.

I was 4 years old when the new medicine started and now I am 5.
The information in this book is provided by BioMarin Pharmaceutical for educational purposes. MMRC/VOS/0189-Mar 2019 (version 1)
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ALBERT
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ANNIE
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BUNNY
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octopus
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ROCKET
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