

GIGI

and Type 1 Gaucher Disease

The story of Gigi is designed as a tool for parents or guardians to use when explaining Type 1 Gaucher disease and treatment to their child.

We hope you enjoy Gigi's story.



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This is the story of our friend Gigi,
a little girl who loves playing and studying.



Gigi lives in a small town in the US and loves her family very much.



This is Gigi's family. Her mom's name is Ann. The man reading the newspaper is Lou, her dad, and the little boy sitting on the floor is her younger brother, Robert.

Gigi was always a very happy child, but just before she turned 8, something seemed wrong.



Gigi started to complain that she got tired very easily when she was playing. She also felt sleepy most of the time.



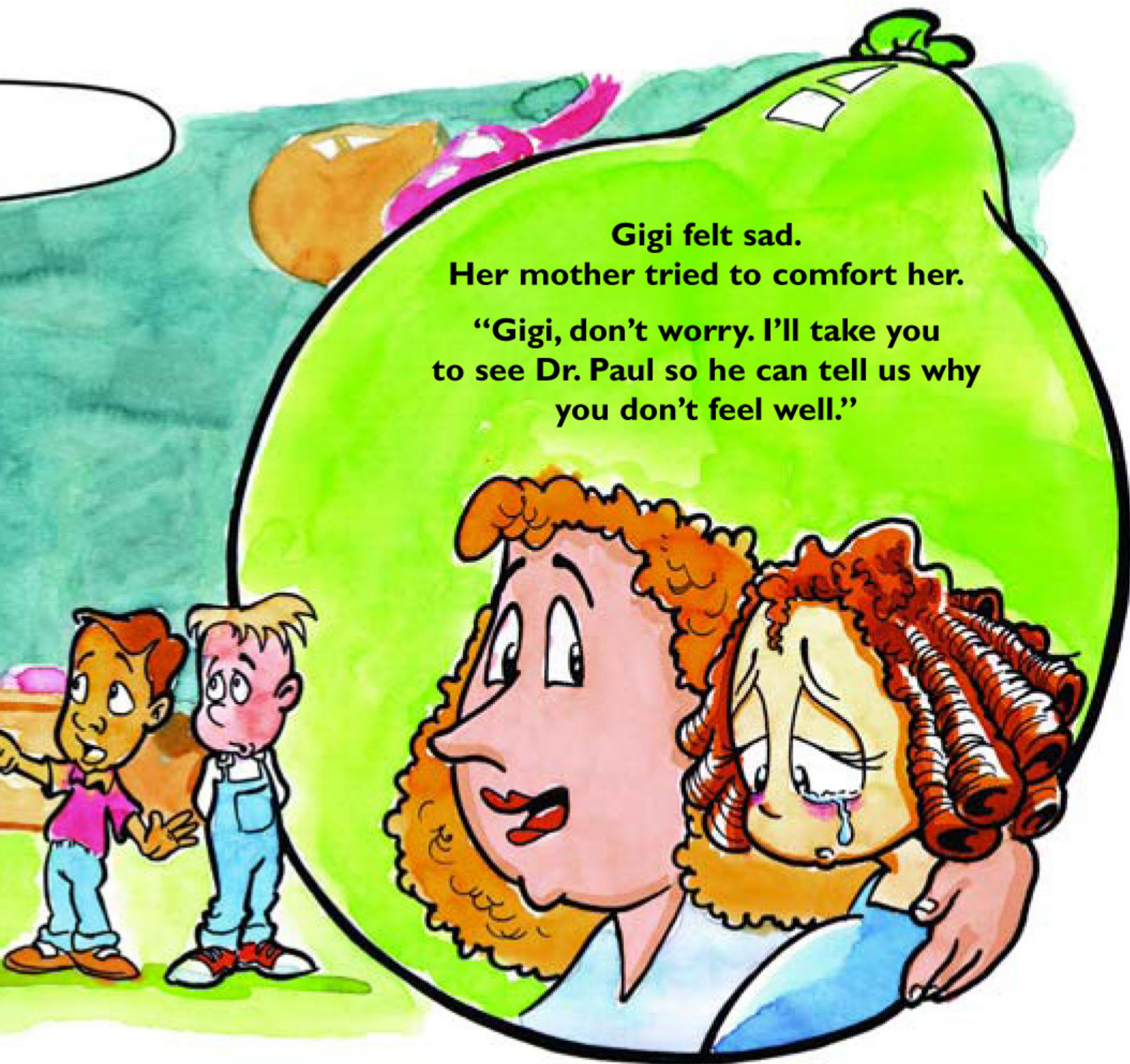


Her mom noticed that Gigi looked thin and that she bruised more easily than her brother.

Other family members noticed changes in Gigi at her 8th birthday party.



**Gigi felt sad.
Her mother tried to comfort her.
“Gigi, don’t worry. I’ll take you
to see Dr. Paul so he can tell us why
you don’t feel well.”**



At Dr. Paul's office, Gigi's mother asked:



“Doctor, do you know what’s wrong with Gigi?”

“Well, Gigi looks pale, she’s too thin, and her belly looks large. But I’ll need to run more tests to find out what’s wrong.”



Gigi had some tests. When Dr. Paul saw the results, he was puzzled. He told Gigi's mother that she should see a specialist.

A few days later, Gigi and her parents took a bus to a nearby city to see the specialist. Some of her friends came to wish her well.





The specialist's name was Dr. Phillip. He was very nice and listened to Gigi when she told him how bad she felt.



I can't play anymore.
I'm always tired.



I can't eat much or bend down
to tie my shoes because
my belly is so big.



**“Is there anything else
that bothers you, Gigi?”
Dr. Phillip asked.**



Well...my nose bleeds a lot.



My dresses don't fit anymore.



When I run, my legs hurt.



And if I fall down, I get bruises right away.



Dr. Phillip thought about what Gigi said and looked at her tests. He called Gigi and her parents into his office. “I think that Gigi has Type 1 Gaucher (pronounced go-shay) disease,” he told them. “We can find out for sure by doing another test. It will take a few days for the results to come back. Why don’t you make an appointment for next week? I’ll be able to tell you then for sure if this is Gigi’s problem.”



Next week, when the test results came back, Dr. Phillip said, “It was just what I thought. Gigi does have Type 1 Gaucher disease.” “What’s that, doctor?” asked Gigi’s mother.

Gaucher disease is a disease that happens when a child has too little of a special enzyme in the body. This enzyme is needed to help remove extra fat from within the body's cells.



It's important that this extra fat be removed from certain organs in the body, especially the liver and the spleen. When the body does not have enough of this enzyme, extra fat builds up in the liver and spleen. This makes them grow too large and prevents them from working the way they should. Gigi's body does not have enough of this enzyme, so her liver and spleen have grown large and are not working well. This is what has made Gigi's belly grow so big and why she feels so tired.



“We’re very worried about Gigi,” said her father.

“Yes,” said Gigi’s mother. **“What can we do to make her feel better?”**



“I know you’re worried, but there are ways we can help Gigi,” Dr. Phillip answered. **“There’s a medicine that helps replace the enzyme that Gigi needs, and that can help her feel better. It’s a medicine that’s given through an infusion. She’ll need to be given this medicine every 2 weeks. There’s a special clinic where you can take Gigi to get these treatments.”**

Before he finished the checkup, Dr. Phillip told Gigi all about the treatment. He told her that the medicine would be given to her by infusion using a needle. “I know needles are no fun, Gigi, but don’t worry. The nurses at the clinic will do everything they can to make you comfortable.”

Then he weighed Gigi so he could figure out how much medicine Gigi would need to receive.



“You can start your treatment tomorrow, Gigi!” he told her.

The next day, Gigi's mom took her to the clinic.

A very nice nurse was there to give her the medicine.

Gigi asked, "Will I have to sit in this chair to receive my infusion?"



The nurse said, "Yes, but it's a comfortable chair, and you can have your teddy bear with you. I'll also be right here if you need me."

The nurse asked Gigi to sit in the chair and then inserted a needle that was attached to a tube into a vein in her hand. Gigi was very brave. “That didn’t hurt too much!” she said after the needle was inserted.

“I’m glad!” the nurse replied. “Now, it will take a while for you to get all the medicine, Gigi, but while you wait, you can watch TV or I can give you some books to read. Your mom can come and stay with you, too.”



While she waited, Gigi watched her favorite TV show. After that, her mom read some funny stories to her. Pretty soon, Gigi had received all of her medicine.

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When the infusion was done, the nurse told Gigi she was very brave. Gigi's mother agreed.

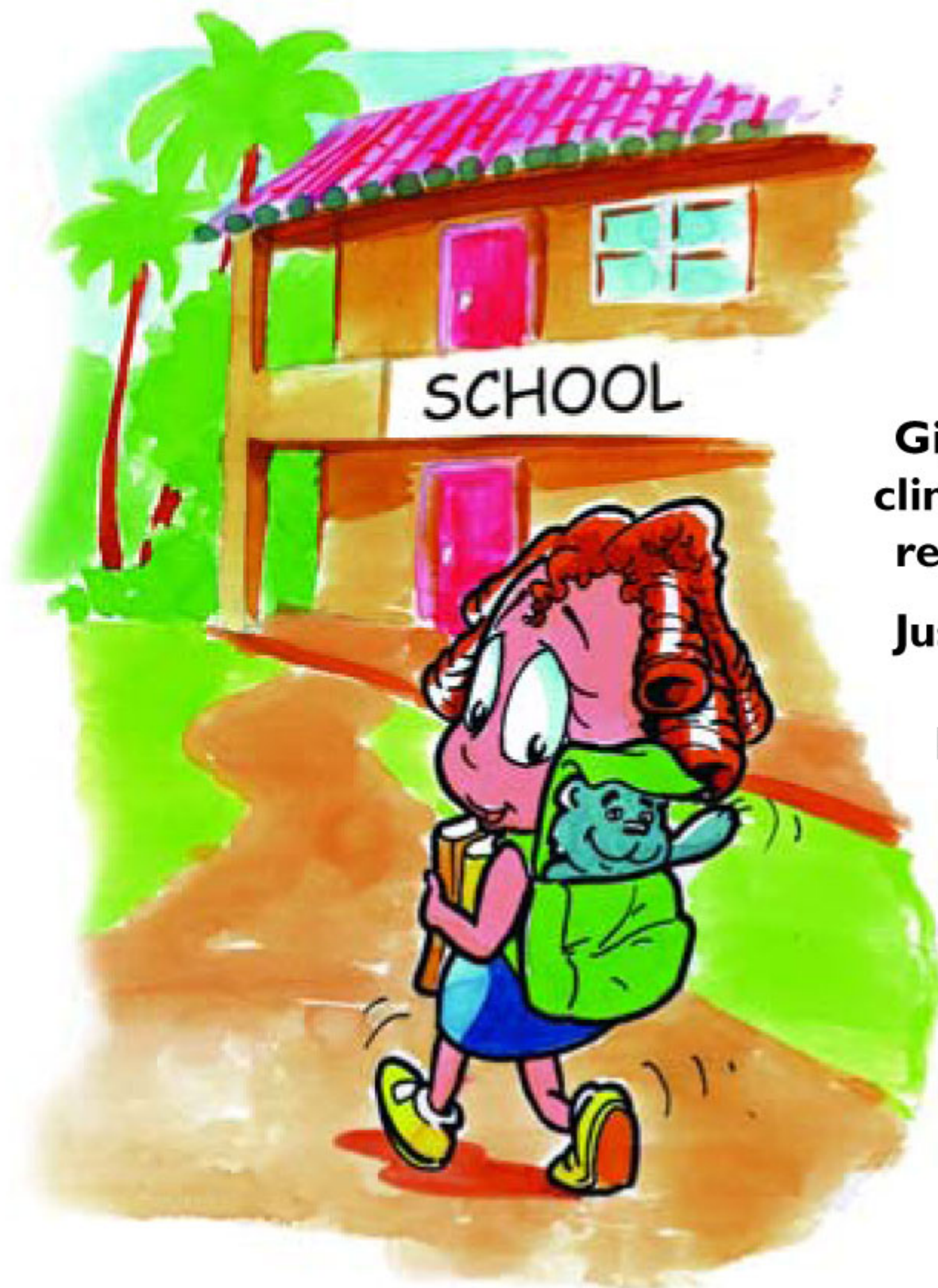
“You'll come back for treatment every 2 weeks,” the nurse told Gigi. “Over time, you should begin to feel better. To keep feeling better, you'll need to keep having these treatments.”



“That's okay,” Gigi's mother said, “as long as it helps Gigi feel better!”

“That's right!” said Gigi.

The nurse smiled. “Okay, see you in 2 weeks! If you have any questions, you can always call Dr. Phillip or me.”



Gigi went back to the clinic every 2 weeks to receive her medicine.

Just as the nurse said, over time, Gigi did begin to feel better.

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Now Gigi is turning 10.



**“Gigi, come inside. We’re going to sing happy birthday to you!”
Robert shouts through the window.**

Gigi is having a nice birthday with her family and friends. Everyone is glad she's feeling better.



Happy Birthday to Gigi



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IMPORTANT SAFETY INFORMATION

Note to Parents:

This book is brought to you by Genzyme Corporation, makers of Cerezyme[®] (imiglucerase for injection). Results for patients receiving Cerezyme[®] therapy vary.

Side effects related to Cerezyme[®] (imiglucerase for injection) administration have been reported in less than 15% of patients. Each of the following events occurred in less than 2% of the total population. Reported side effects include nausea, vomiting, abdominal pain, diarrhea, rash, fatigue, headache, fever, dizziness, chills, backache, and rapid heart rate. Because Cerezyme[®] therapy is administered by intravenous infusion, reactions at the site of injection may occur: discomfort, itching, burning, swelling or uninfected abscess. Symptoms suggestive of allergic reaction include anaphylactoid reaction (a serious allergic reaction), itching, flushing, hives, an accumulation of fluid under the skin, chest discomfort, shortness of breath, coughing, cyanosis (a bluish discoloration of the skin due to diminished oxygen), and low blood pressure. Approximately 15% of patients have developed immune reactions (antibodies); periodic monitoring by your physician is suggested.

Patients should notify their physician immediately if they experience any side effects with treatment. For more information, consult your physician. Please see accompanying full product information, or visit our website at www.cerezyme.com, or contact Genzyme at 1-800-745-4447.