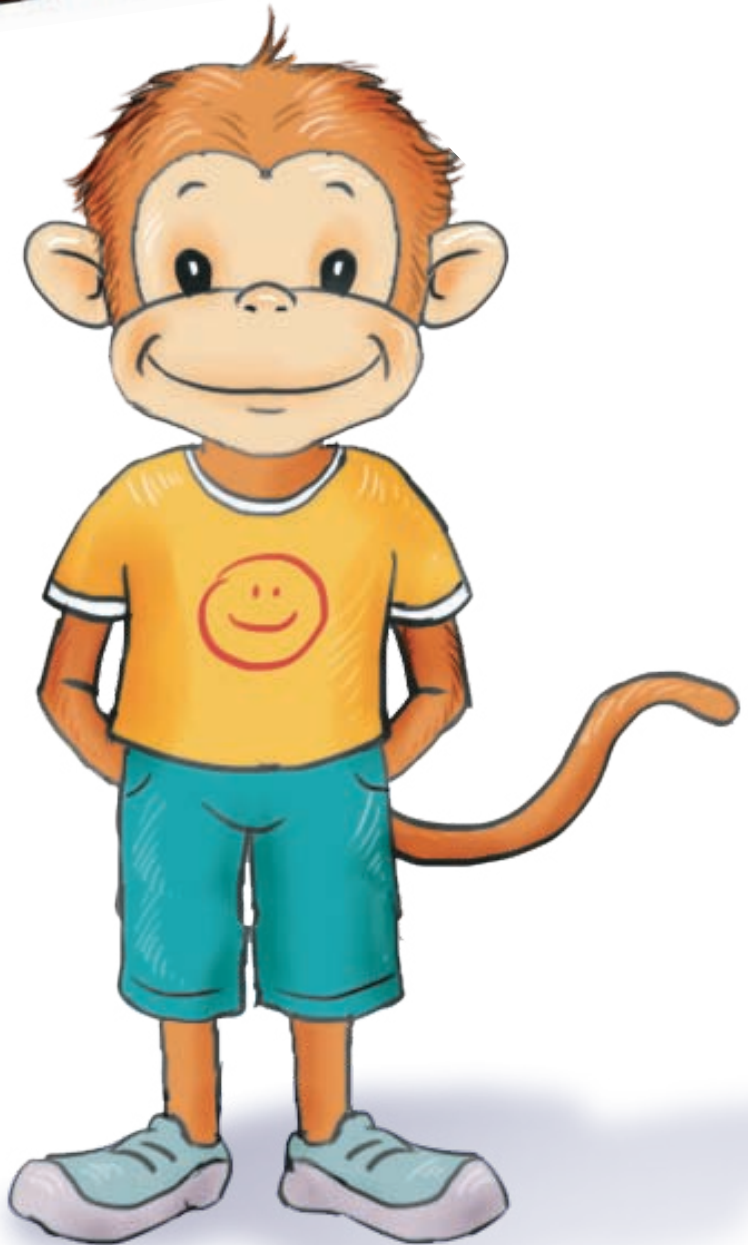


KIPPO

A book for
children about
Juvenile Idiopathic
Arthritis

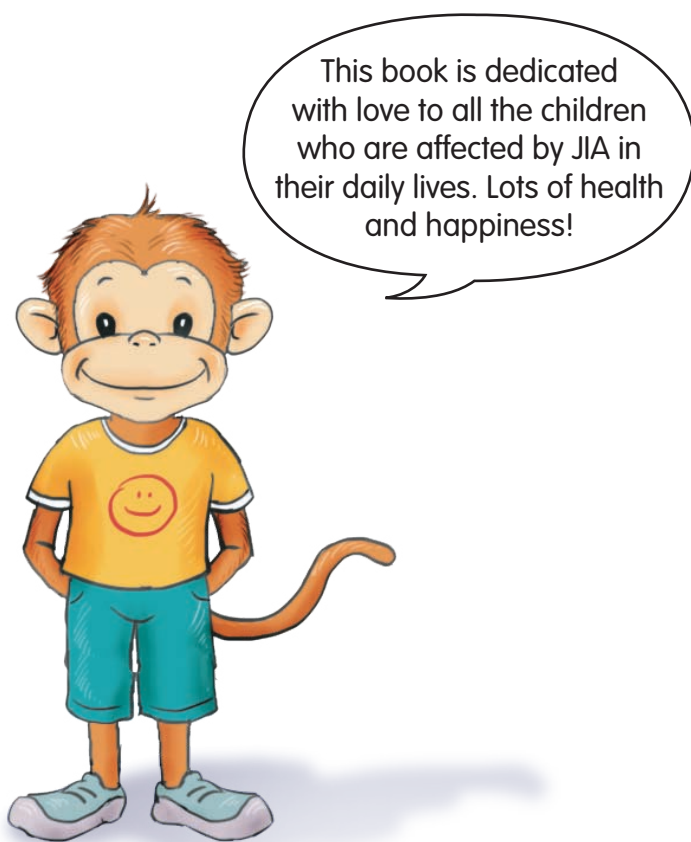


KIPO

Written by Tsipi Egert and Ruti Vitman

Illustrated by Dror Adam

Edited with permission by iCAN Irish Children's Arthritis Network



KIPO: A book for children about Juvenile Arthritis

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WHY ARE KIPO'S JOINTS SORE?

Dear Parent,

This book was written by parents of children suffering from JIA, for the benefit of other JIA children and their families.

A child who is sick with JIA often feels confused and afraid. He doesn't understand why he is sick and sore, and he worries about the frequent doctor and hospital visits, as well as the medications and shots to which he is subjected. It is important that you, as parents, mediate between your child and these difficult circumstances, and explain to him about his condition. This will help relax your child, and give him strength to deal with what he is going through.

The purpose of this book is to open communication channels between you and your child. This book will give you tools to understand how your child is feeling, and to explain what JIA is. In this book, we have assembled many of the children's challenges, including practical tools for coping with them. All of this is through identifying with Kipo the monkey, who also has JIA.

HOW TO USE THIS BOOK

The pictures are designed to be used as springboards for discussion with your child. We suggest that you pause at each picture, taking time to ask your child, "What does Kipo find difficult?" "Why is Kipo crying?," "How do you suggest Kipo solve this difficulty?"

To simplify and shorten this book, we have kept the text brief. We encourage you to adapt the text and expand it to include symptoms specific to your child's illness. Following are suggested discussion topics by picture:

- **PAGES 8-9:** Focus on discovering the nature of Kipo's difficulty. We suggest that you expand the text line to include the symptoms your child is experiencing: fever, rash, uveitis, other joint involvement, etc.
- **PAGE 10:** Finding ways to deal with pain, what works for your child?
- **PAGES 12-13:** Which games and activities are difficult? What can your child play instead?
- **PAGES 14-15:** Familiarising your child with the hospital: What does the nurse do? What is an IV?
- **PAGES 16-17:** What does the doctor's examination include? What is JIA? Learning how to use a pain ruler in order to understand how your child is feeling.
- **PAGES 18-19:** Getting acquainted with the care staff.
- **PAGES 20-21:** Physiotherapy and its purpose.
- **PAGES 22-23:** Practical tools for dealing with the injection. Ask your child what helps him most to handle the injection.
- **PAGES 24-25:** Emotional processing: recognising emotions, fatigue, and pain while focusing on the bright sides of life.
- **PAGES 26-27:** Your child's illness is secondary to his identity as a fun loving individual.

With appreciation to the doctors and healthcare workers who help make our children's life better. And many thanks to the Doctors, translators, editors and anonymous donors who made this book possible.

WHAT IS JIA (JUVENILE IDIOPATHIC ARTHRITIS)?

Considered the most common form of arthritis (up to 1 out of 1000 kids), Juvenile Idiopathic Arthritis (JIA) begins before age 16, and involves swelling in one or more joints. Each episode lasting at least six weeks.

JIA may include a variety of symptoms such as muscle and soft tissue tightening, bone erosion, joint misalignment, and changes in growth patterns. Not all symptoms are shared by all children with the disease. Moreover, the symptoms of JIA can change from day to day. Since children are growing, it is important to treat JIA with the aid of medicine and physiotherapy. This helps to prevent damage to the joints and bones, and helps to maintain healthy social development. Since the eyes can also be affected (uveitis), periodic eye examinations are important.

JIA is an autoimmune disorder, which means that the immune system malfunctions and attacks the body's own organs and tissues. Each individual case of JIA is sub classified to determine the appropriate treatment.

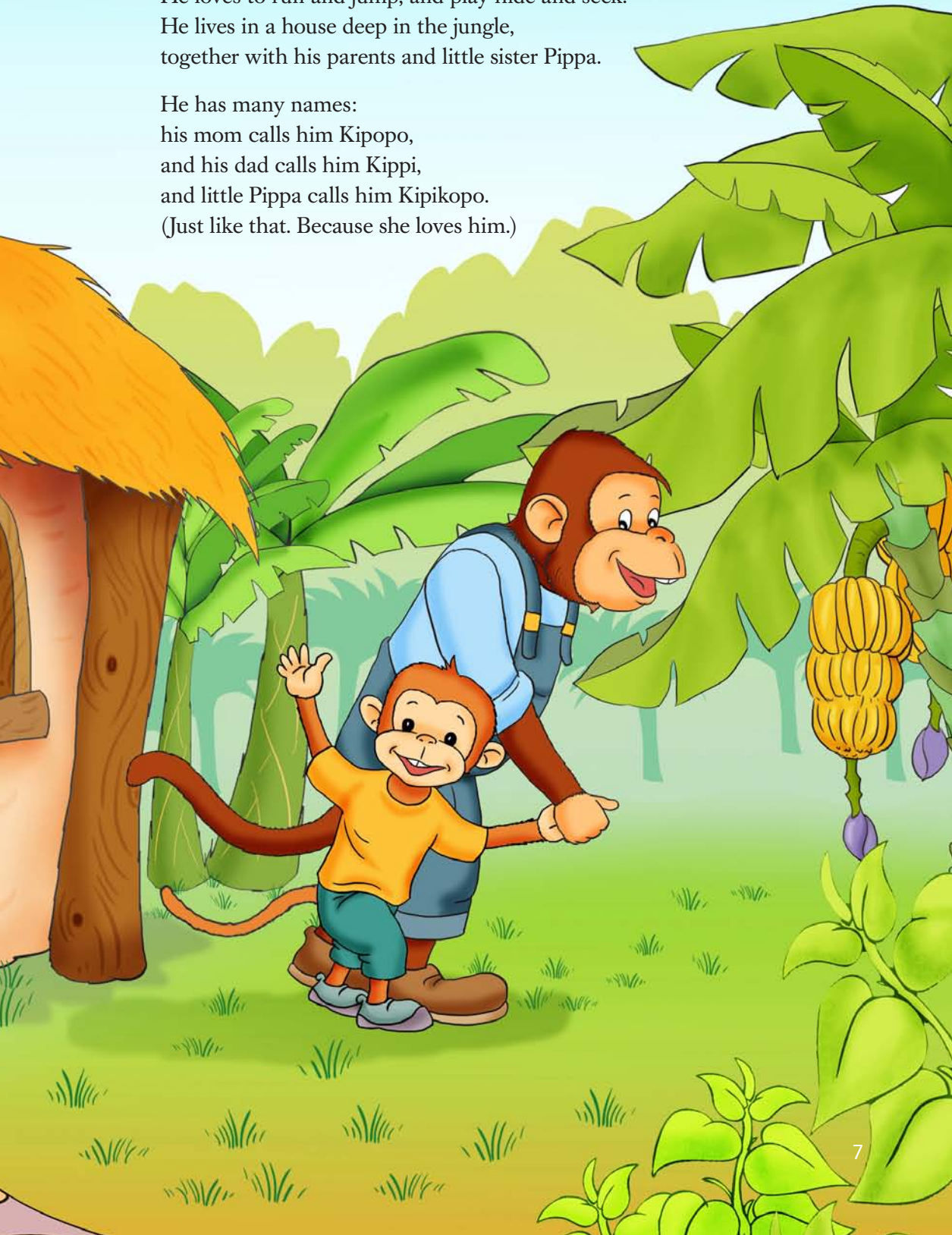
You are not alone!

iCAN hosts a private online forum on Facebook for parents of children and teens in Ireland with JIA. This is an excellent source of information and support for so many families dealing with this disease. If you would like to join the iCAN Facebook private forum, please message us on our public facebook page at: www.facebook.com/icanireland or email us at: icanireland@gmail.com



Kipo the monkey is small and sweet.
He loves to run and jump, and play hide and seek.
He lives in a house deep in the jungle,
together with his parents and little sister Pippa.

He has many names:
his mom calls him Kipopo,
and his dad calls him Kippi,
and little Pippa calls him Kipikopo.
(Just like that. Because she loves him.)





It's morning in Kipo's home.

Daddy hurries Kipo to come and eat, but Kipo cries out, "I caaan't!"

His Mommy says, "Hurry, your friends are all waiting at school!" But Kipo weeps, "Ow, Mommy! I feel so sore!

Everything is going wrong!"



Mommy sees that Kipo is crying and cuddles him.

“I understand that your morning didn’t start too well... Let’s put Hippo the hot water bottle on your sore knee. That should help it feel better. If you need, I’ll give you some medicine to take away the pain. In the meantime, we can relax together and read a story.”



Then Mommy suggests, “Kipopo, let’s gently bend your leg... and then straighten it again. There! Doesn’t it feel better already?”

After a while, the pain isn't so bad any more.
Kipo plays hide and seek with Pippa.

"Kipopo – are you O.K. now? Do you feel ready for school?"
asks Mommy.

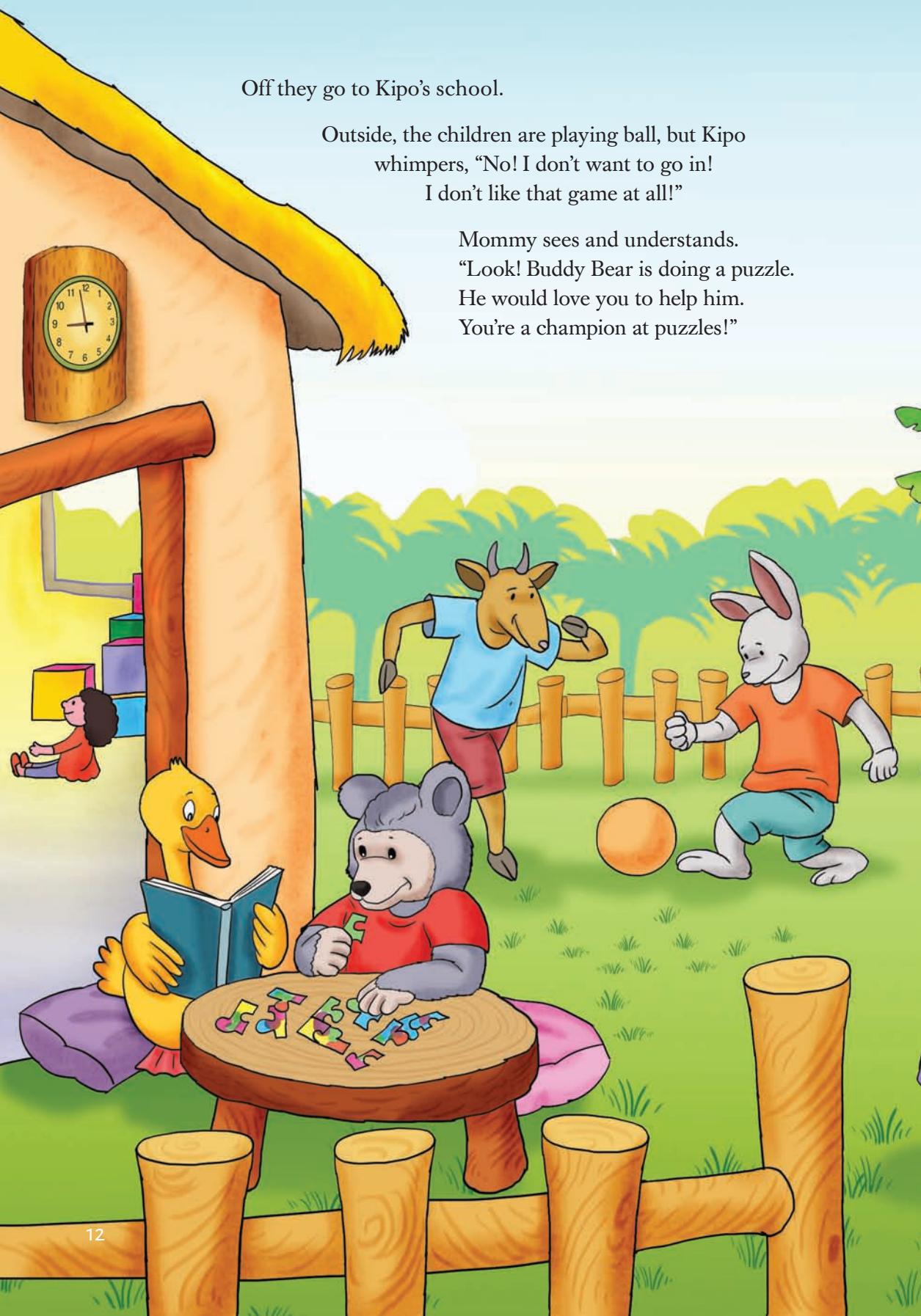
"Yes," responds Kipo. "My friends are waiting for me!"



Off they go to Kipo's school.

Outside, the children are playing ball, but Kipo
whimpers, "No! I don't want to go in!
I don't like that game at all!"

Mommy sees and understands.
"Look! Buddy Bear is doing a puzzle.
He would love you to help him.
You're a champion at puzzles!"



Clover, the school teacher, sees them at the gate and comes over. “Kipo, we’re so glad you came! If you feel pain in your joints, just tell me and I’ll find you a quiet place where you can relax with your friends.”

“Kipo,” his mom reminds him, “this afternoon we have a meeting with Doctor Jointy. We’ll tell him about your difficult morning, and ask him to explain what’s happening in your body.”







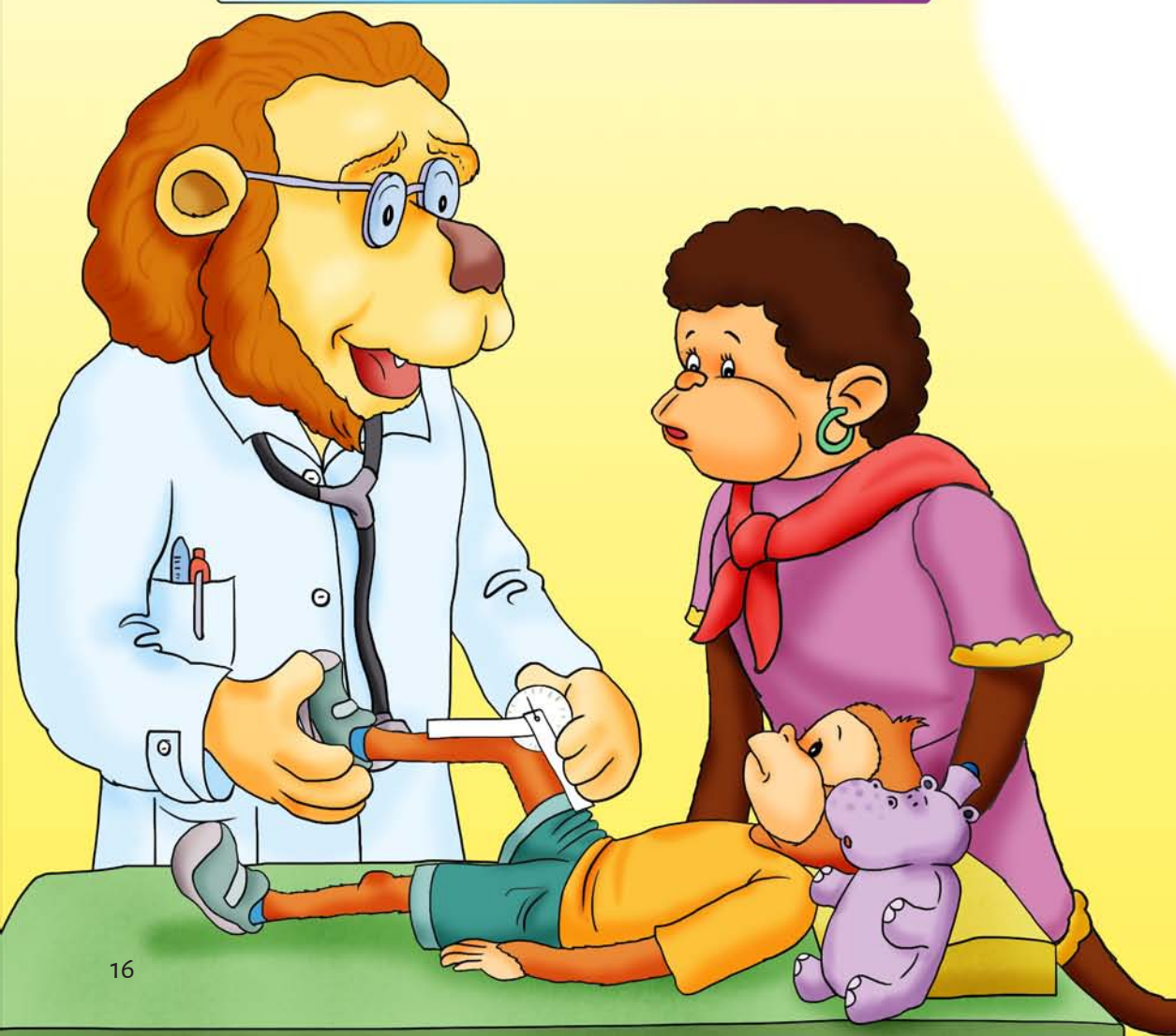
The hospital waiting room is full of commotion.

Receptionist and doctors, nurses and children!

Suddenly the door opens and out pops a head. It's Doctor Jointy!
"Kipopo, you're here. That's great!"

Into the office they step, and Dr. Jointy examines Kipo's joints.
"I hear you had a hard morning."

"Look at this Pain Scale on the wall. It will help you express
how you feel. The happiest face means you feel really good,
when nothing is sore. The saddest face means you feel terrible.
Which face describes how you feel now?"





While Kipo is busy thinking, Dr. Jointy explains to his parents, “Kipo has JIA, Juvenile Idiopathic Arthritis. These long words mean his joints get swollen and sore. We don’t know why children get it, but it’s important to know that it isn’t catchy, and your Kipo is a normal little monkey who is happy to learn, play, and laugh.

Sometimes, he will have bad days when the pain will make it hard to walk, run, draw, or even chew food. But not all days will be bad. You are all experiencing a difficult time now. Kipo has to go through many tests, and it will take a while till we get his medicines just right and he starts to feel better.”

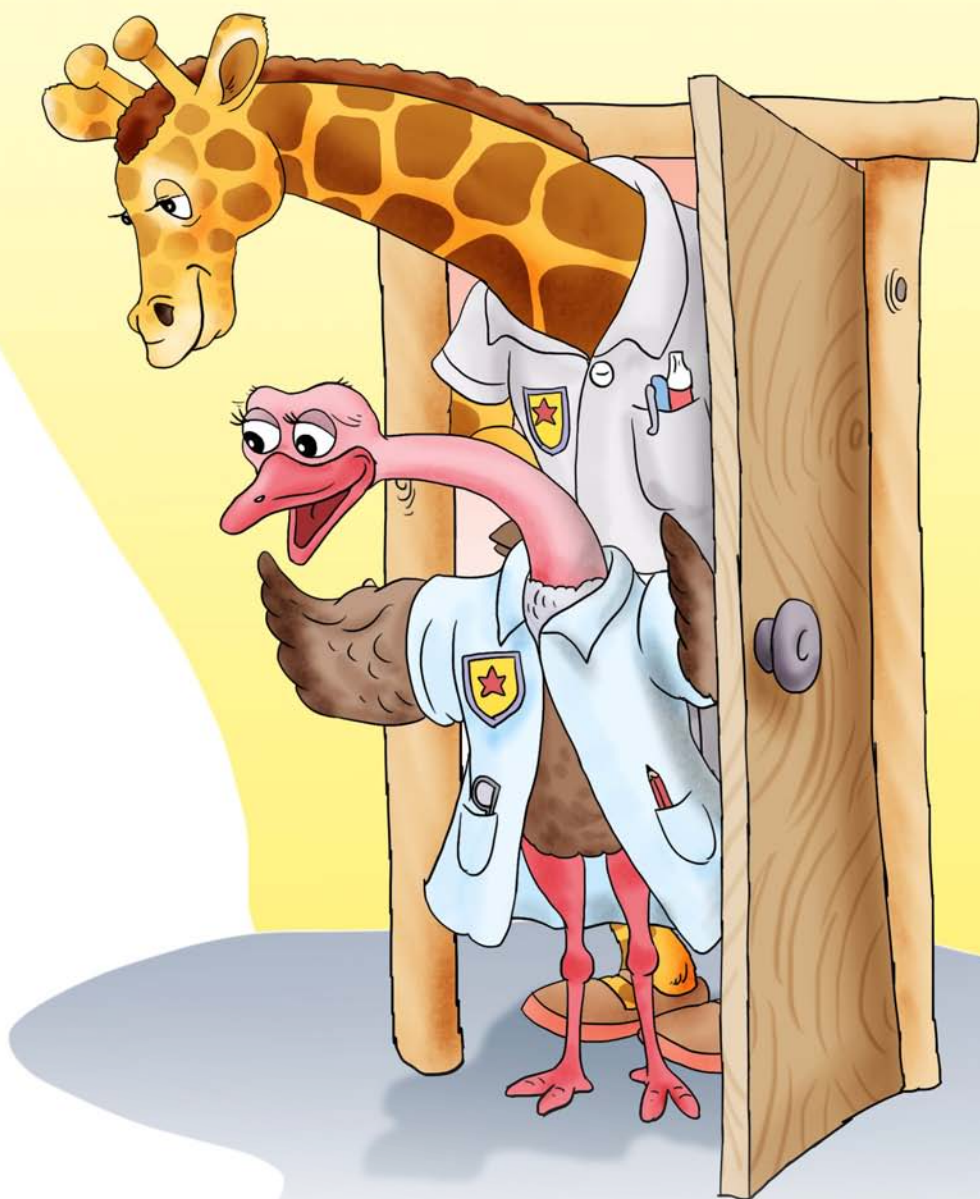
Daddy asks, “Can you explain to us what is happening in Kipo’s joints?”

“Look Kipo,” the Doctor points to the picture on the wall, “this is what your joint looks like inside. It has an inflammation that makes it swell and gives you pain. Now you are feeling pain in your knees and fingers, but the swelling can also appear in other joints. Sometimes JIA can harm the eyes, even without you noticing. When your joints are swollen you feel terrible and it’s hard to move around and play.”

Kipo groans, “I don’t like it when it hurts! It’s not fair!”

Dr. Jointy nods, “You’re right. It’s not pleasant, but we’re all on your side, and we are fighting JIA together with you!”





The doctor gives everyone a colored tag that says,
'We are Kipo's Fighting Force!'

"I, Dr. Jointy, am the head of the force. I will give you
medicine and injections that will fight the inflammation.

We also have two other fighters, Mrs. Stretchy, who will
help make your muscles stronger, and Dr. Ossie Eyes,
who will make sure your eyes stay healthy.

The main helpers are Mommy and Daddy who love you
very much.

And you, Kipo, you are the Champion!"

After the meeting with Dr. Jointy, the family goes into Mrs. Stretchy's room. "Hi Kipo. How are you? Let's see how you jump like a frog in a pond!"

Kipo is happy to stretch, bend, and jump. Mrs. Stretchy is pleased. "You're doing great Kipo! If you practice every day for a few minutes, you'll be able to run and play without any problem when the swelling is down."

She tells Mommy and Daddy, "Kipo should do the exercises also when the inflammation goes down, so that his joints will be flexible and his muscles will be strong."





From the hospital, they continue to the clinic.

“Kipo, we’re going to see the nurse. Today is the day for your injection.”

“No, no!” shouts Kipo. “I hate injections!”

Mommy says, “I know that an injection hurts, but there is no choice. This is the best way to fight the inflammation. You can sit on my lap and I’ll hug you tight while the nurse gives the injection.”

But Kipo is not calm. He still feels afraid.





When they get to the clinic,
Mommy cuddles Kipo.

“Kipo, my sweetheart,
this injection is important.
It will help keep you well.
You can’t choose whether
to receive it or not, but you
can choose whether you want
to get it in your arm or
in your leg. “Should we put
some freezy spray on the spot to numb it?”

“And of course,
we can read a book together.”

Kipo stretches out his arm
and shuts his eyes tight.

He feels a small prick and
counts with Mommy,
“One-two-three.”



Daddy says, “You’re
a real brave fighter!”

And Mommy asks,
“Does it still sting?”

“Just a little...”

It's night time and the stars are out. This was a long day. "I'm so tired," sighs Kipo. "I don't like the hospital or the injection, and now my knee feels sore again..."

Mommy replies, "I'm sorry, my dear. It may take some time till you start feeling better. Meanwhile, we'll all fight bravely together."

Kipo nods, "Yes."

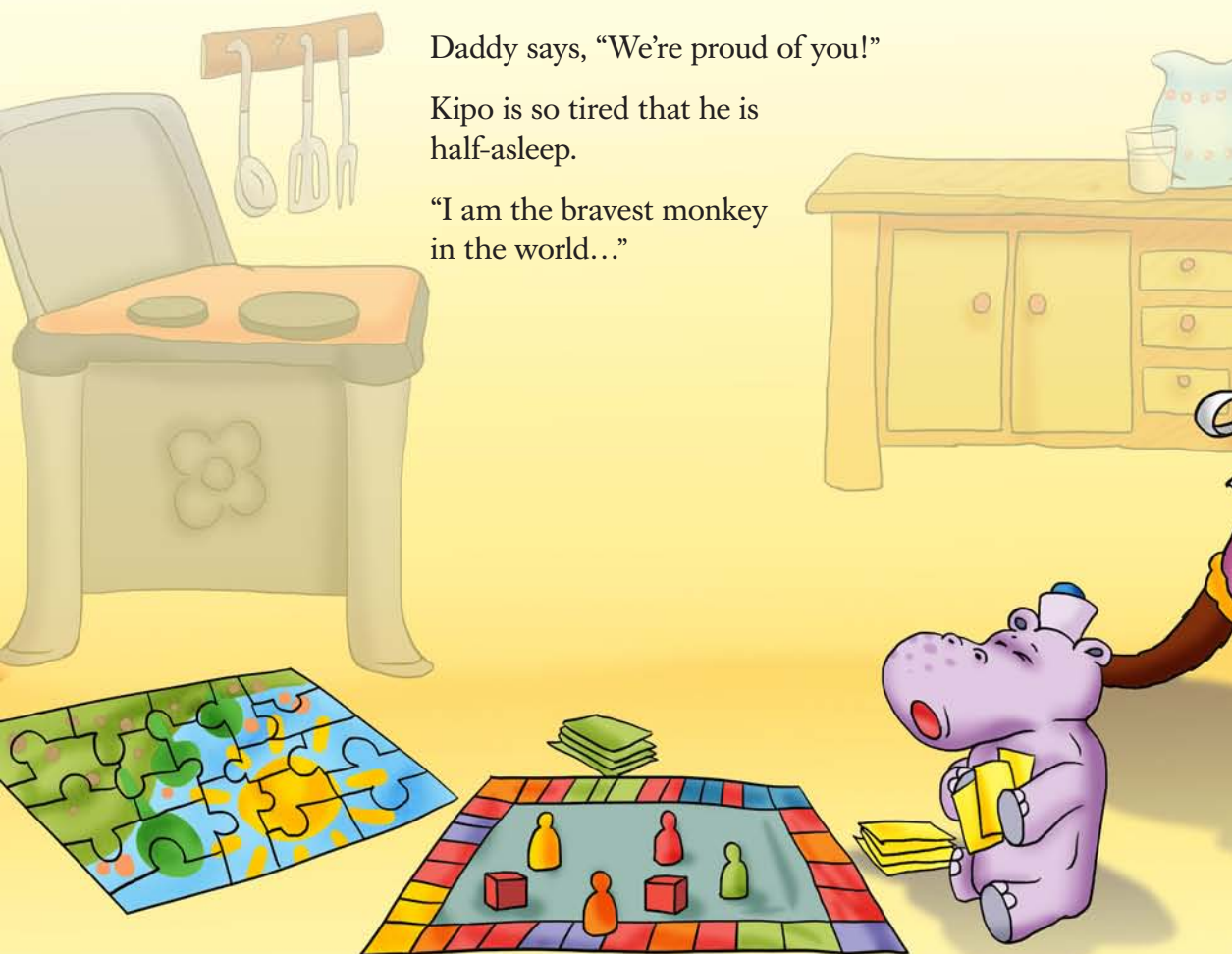
"You know," Kipo says, "Dr. Jointy gave me a sticker and Mrs. Stretchy was fun. I even won the game that we all played together!"

Mommy smiles, "You're a real hero. I'll give you two hugs and a kiss."

Daddy says, "We're proud of you!"

Kipo is so tired that he is half-asleep.

"I am the bravest monkey in the world..."





Kipo is a sweet monkey who is full of fun.
Sometimes his joints hurt him a ton.
He loves his friends and hates his shots,
but as a big monkey he understands,
that not everything in life goes as planned.
Kipo the champion, with friends, family, and the help of all,
is happy, laughing and standing tall.







This book was printed and distributed by iCAN Irish Children's Arthritis Network, made possible by generous donations to iCAN. Special thanks to Tsipi Egert and Ruti Vitam for sharing this book with iCAN and granting permission to reproduce and edit this publication for children in Ireland with JIA.

iCAN is a volunteer Irish charity, run by parents of children and teens with JIA. Our mission is to provide support and information and to advocate for best care for those affected by Juvenile Idiopathic Arthritis.



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