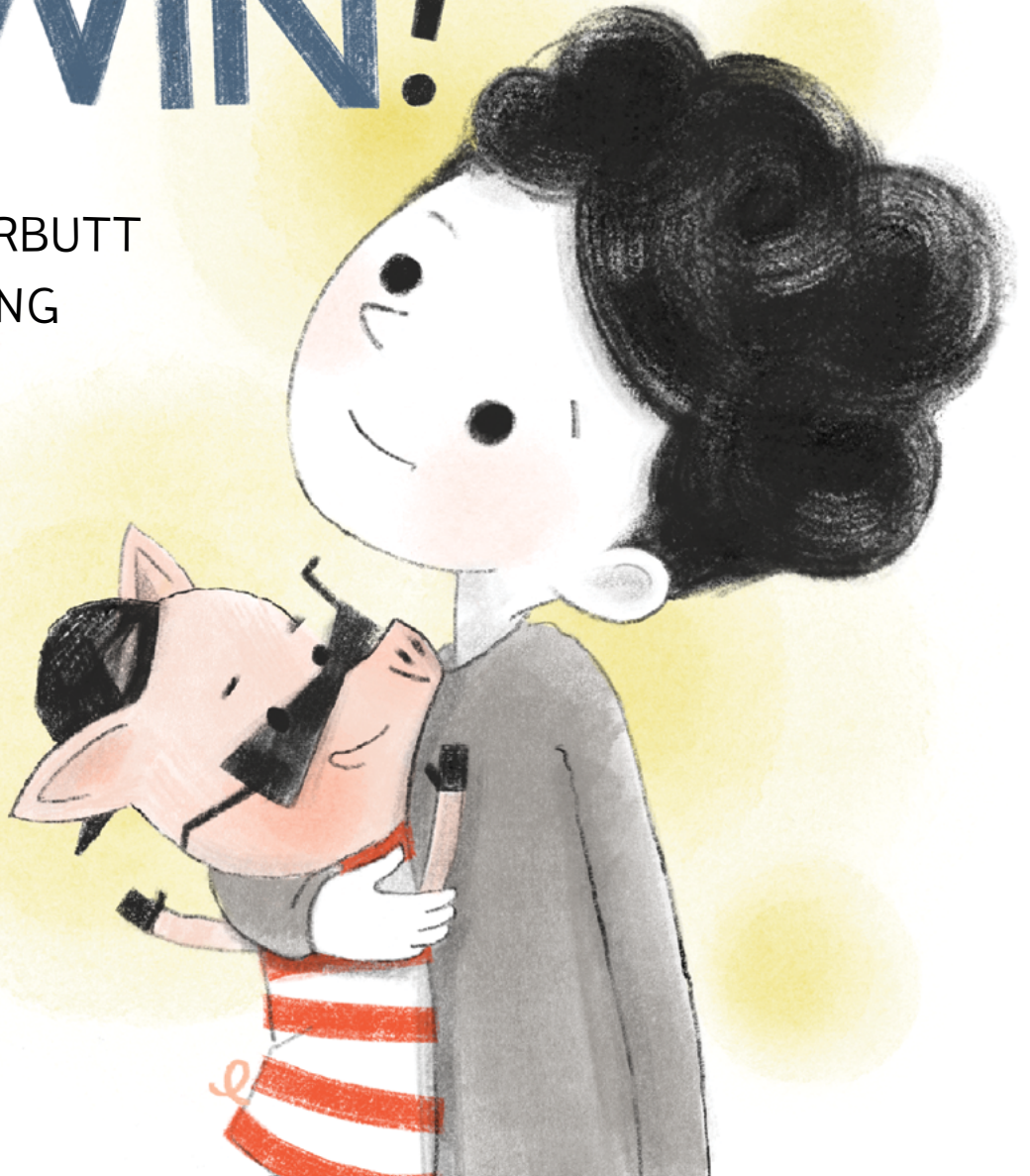


It's in ME to WIN!

LORETTA GARBUTT
JESSICA SPRING





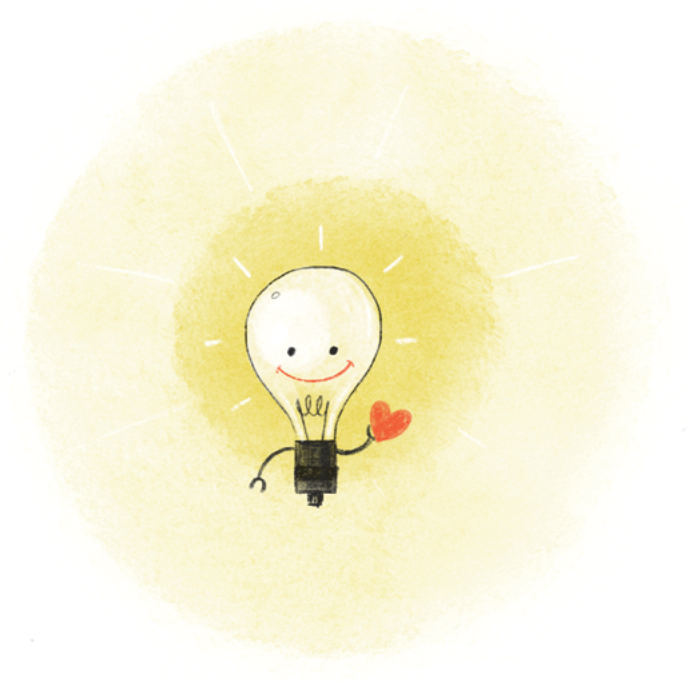
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Published in Canada by AAMAC
aamac.ca

ISBN 978-1-7775464-0-3





VERY big thank you's to Andy, Leah and Karlee
and to Stephanie and her daughter Francesca.

Thank you, Kelly Walker, for taking the time
to share your procedure while in treatment.

All of you helped me to understand this disease
and enabled me find the words to make a story.

This story is a general and simplified description
of the process of diagnosing and treating
aplastic anemia.

Everyone has a unique experience and not all
the steps have been covered in detail.

My soccer team had practiced hard for weeks but on the day of our semi-finals, I didn't have my 'champion burst of speed'. I was short of breath and tired all the time.





We made the finals that day but I had a fever, so mom took me to see Dr. Finn.

After a few weeks and a whole bunch of tests that I didn't want, I had to have another one, a **bone marrow** test.



Bone marrow is the spongy material in the centre of our bones.

“A physical exam doesn’t show everything,” Doctor Finn said.
“We’ll take a small sample of your bone marrow and put it under a microscope.”

I didn’t really like the sound of that.



Bone marrow makes new blood cells and there are three types: 1—Red blood cells carry oxygen through our body, 2—White cells fight infection, 3—Platelets help control bleeding and clotting after injury. Young blood cells are called **stem cells**.

DIAGNOSIS

This test showed that I had something called **aplastic anemia**.
I didn't know what that meant.

"It's a disease," said Dr. Finn.
"Your bone marrow is not
producing **red blood cells** like
it should. That's why you haven't
been feeling well."

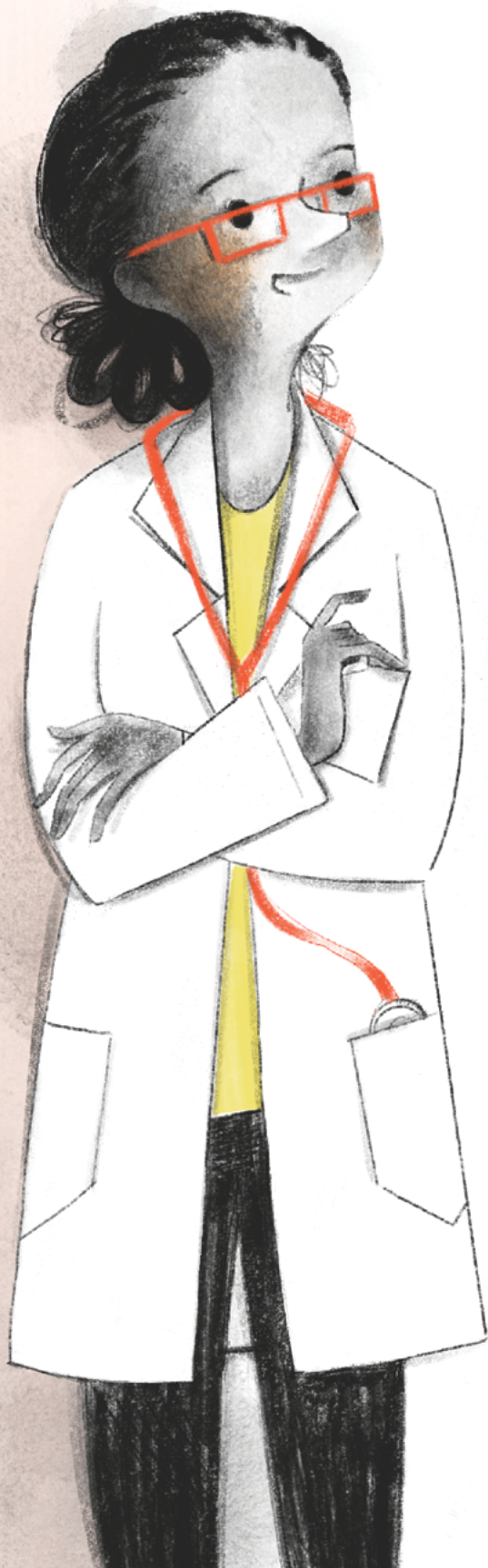
Aplastic anemia is a condition that occurs
when bone marrow fails to make enough
healthy blood cells.





“Think of it like this, there’s a bug in your blood that’s eating all your red and **white blood cells**. It can be serious.”

The word serious made me think of my teacher when my homework isn’t done.



“You’re young, which means you have a stronger way of fighting things. You’re still growing and that gives you special powers.”

‘**Special powers**’, I thought.
I have a disease but I also have special powers?

“We will take out your unhealthy bone marrow and put in new, healthy bone marrow.”



I didn't understand much of this but I did understand that my bone marrow wasn't doing the job it should.

When bone marrow stops working, the young blood cells, called stem cells, are removed because they aren't healthy. They're replaced with healthy stem cells that will grow and become new, healthy bone marrow.

WHEN
IS THIS
GOING TO
STOP?

I just want
to play
with my
friends!

WHY
ME?!

WHY
can't I
be like
everyone
else?

How can I
be BRAVE?!

How can I
beat this?

THIS ISN'T
FAIR!!



I was scared and I cried. I had so many questions.



“This is difficult for you,” Mom and Dad said.

“We will be as brave as we can.”

Even with their hugs, I wasn’t sure how to be brave.

MY DONOR

The next step was to find a ‘**donor**’.
Someone with healthy bone marrow.

A few people were tested and my older sister was a match.

“I’m willing to be your donor,” she said with a smile.
“But you owe me.”

A **donor** is someone who has a good match to your blood type and can share their healthy bone marrow. A brother or sister, even a parent may be a good match.



Now it was her turn to be brave so she dyed her hair purple for the procedure.

“Makes me feel tough,” she said. My sister is the best!



CHEMOTHERAPY

My whole family went to the soccer finals. I was too tired to play but it was great to see my team. I got lots of hugs and smacks on the back.

“I’m going to start **chemotherapy** treatments,” I told them.
“I need to get rid of my unhealthy bone marrow and then my sister’s healthy bone marrow gets put in.”



High doses of **chemotherapy** or **radiation** (sometimes both) will be given to destroy existing bone marrow. The unhealthy cells causing the illness will be destroyed too.

Some of my friends thought that was gross,
some thought it was cool, some didn't say
anything and I knew how they felt.

"You're very brave," my coach said.
But I didn't feel that way at all.

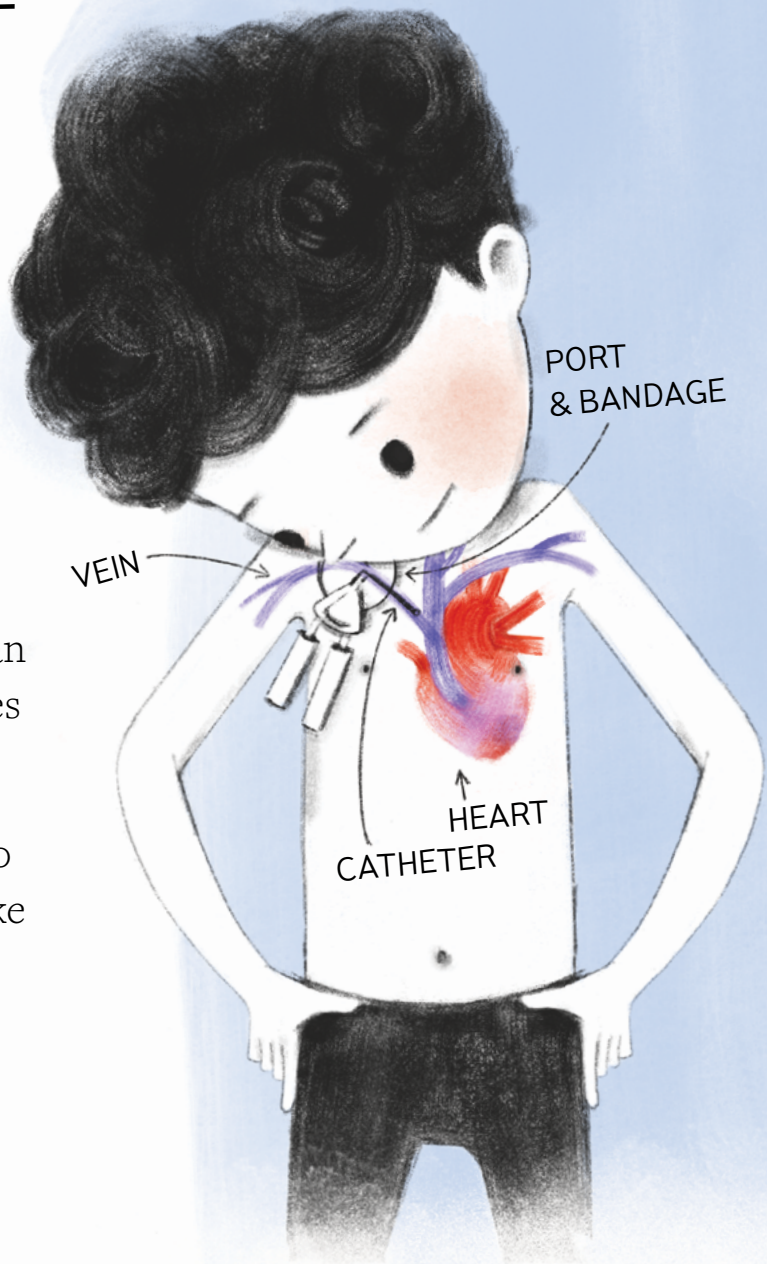


CENTRAL LINE

Everything started kind of quickly. I was going to the hospital a lot more than going to school. The nurses gave me a ‘**central line**’.

“This way we don’t have to pick you all the time to take blood.”

I was so tired of being picked!



Doctors place a **central line** into the skin. This is a small operation where a line is placed close to the heart to pump medicine and helpful blood products through the body.

A central line can stay in the body longer than a regular IV. It gives the medical team a way to give medicines and collect blood for testing without poking you with a lot of needles.



Mom helped me pack a suitcase for the hospital because I'd stay for about 3-8 weeks. That's a long time without my friends and soccer.



I packed books, video games, puzzles and grabbed my stuffed pig, Otis. He wears sun glasses that make him look cool.

Then I had an idea. I rummaged through my closet and found a pair of my own sunglasses.



We both looked cool.
But also, I felt like I was still *me* behind the glasses.
That made me feel a little braver.
Maybe I'd found my special power?

TREATMENT

When I had chemotherapy treatment, I felt sick and really tired. But my glasses were like my protective shield.

The chemotherapy was tough. I got cold and hot, a fever and achy too. How could something that made me sick, make me well again?



But, I hung onto Otis and he hung onto me.

High doses of chemotherapy stop the growth of unhealthy cells. The bone marrow becomes empty. This is needed to make room for the new, healthy stem cells to grow. It also creates a new system to make new blood cells.

Then Otis and I went into **isolation**.
We wore our sunglasses all the time.

Even though I had my 'special power',
I still got upset, a lot. I couldn't see
many people, in case I got a cold from
them.



Isolation is a very clean environment, it helps reduce the chance of infection. A patient may be there for about 20-25 days/4 weeks. That's usually how long it takes for the new bone marrow to start producing blood.

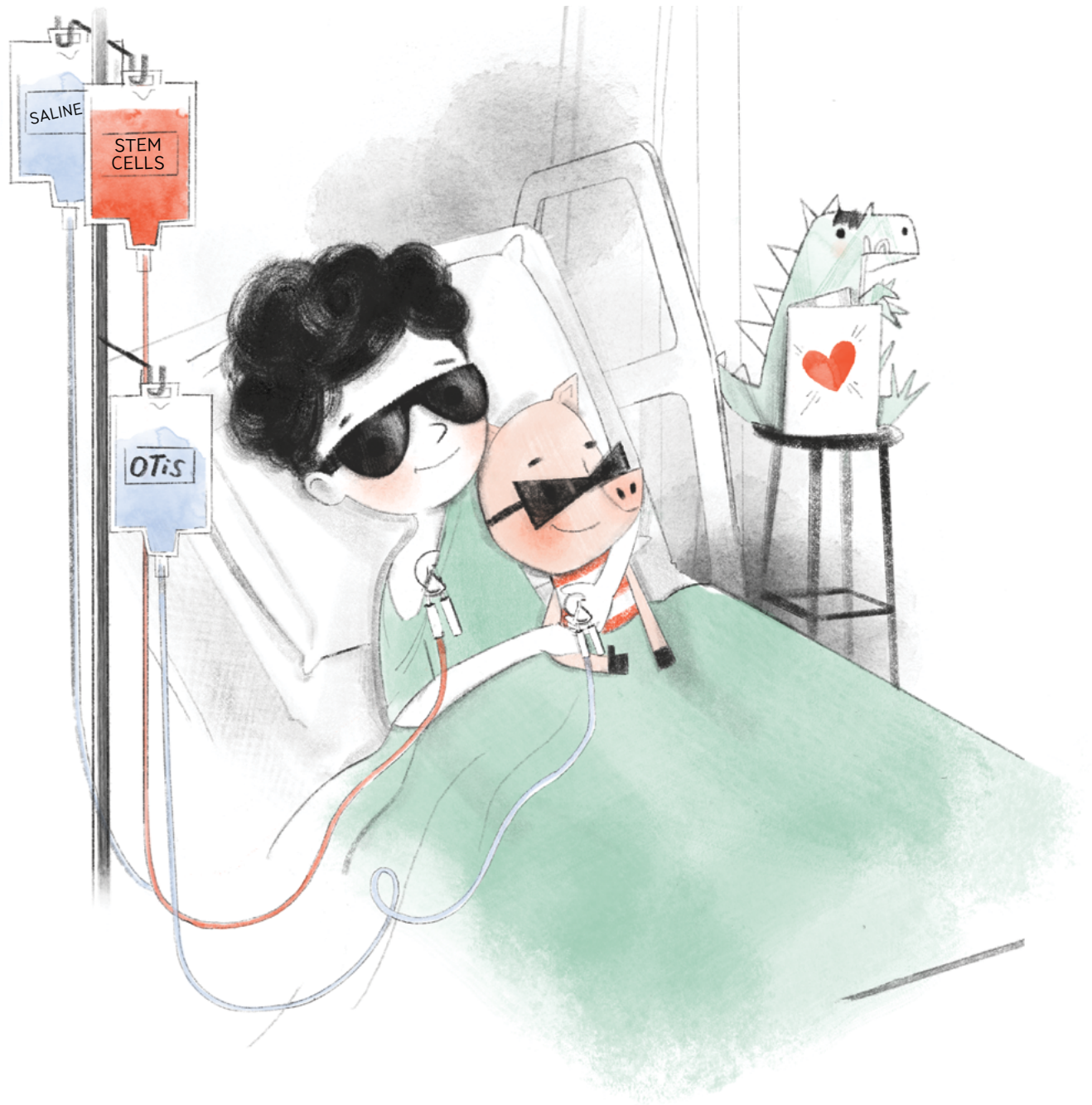
Parents and family must wear a mask and gown when they visit. Antibiotics are given to fight any infections.

TRANSPLANT

The chemotherapy got rid of my bad bone marrow and that was a good thing because I was ready for my sister's healthy donor cells to do their job.



That idea felt weird but kinda good too.
I have my sister's blood in me!



Then, the donor stem cells are given. They find their way into the bone marrow and start growing to make new, healthy blood cells. Sometimes in the first 30 days after the transplant!



The nurses took blood every day from the central line and the **CBC** numbers were posted on a **whiteboard**. We watched to see if my **neutrophil** count was growing.

The complete blood count (**CBC**) is a group of tests that evaluate the cells that circulate in blood, including red blood cells, white blood cells and platelets.



It was! My sister's cells were becoming mine.
We were fighting back together!

A **whiteboard** is a communication board where information is posted.
Neutrophils are white blood cells. The body begins to produce white blood cells on their own.



During all of my illness
and the getting better part,
I saw doctors and nurses every single day.
They asked questions, took my
temperature and were really kind.

There was a storm of words all around me.
'Fight, procedure, transplant, hope.'
I liked the word 'hope' the best.

My friends and family sent cards and
messages, they called me too.
Everyone wanted to help me
get better.



HOPE





And guess what? I did get better.
Bit by bit, my life slowly got back to normal.
Otis and I got new sunglasses.

Even though it was a tough time, I was never
alone. No one knows why I got sick, why it
happened, but everyone took care of me.

Now I can kick the soccer ball around with
my friends again.



And, I have another special power... My left foot!

GLOSSARY

Aplastic anemia

Aplastic Anemia is a condition that occurs when bone marrow stops working and doesn't make enough healthy blood cells.

Bone marrow

Bone marrow makes new blood cells. It is the spongy material, that is found in the centre of our bones.

Bone marrow transplant

A medical treatment when doctors replace unhealthy bone marrow with healthy blood stem cells. Then, the donor stem cells are added and they find their way into the bone marrow to start growing and making new, healthy blood cells.

Bravery

Finding the strength to face a difficult situation such as pain or danger. To have courage. There are many ways to be brave during a difficult time such as, holding something that is special to you, like the child in this story who holds Otis. You can feel brave by wearing something that makes you feel stronger, a cape, magic hat, bracelet, prayer or quote. Is there a fierce animal you can identify with that has strength? Even writing about how you feel in a journal can help.

CBC

The '*Complete Blood Count*' is a group of tests that evaluate the cells that circulate in blood, including red blood cells, white blood cells and platelets.

Central line

A line that is placed close to the heart to pump medicine and helpful blood products through the body. It's also used to draw blood for testing.

Chemotherapy

Treatment that uses drugs to stop the growth of unhealthy cells causing the illness. *Chemotherapy* is also given before a bone marrow transplant to allow better acceptance of the donated bone marrow cells.

Diagnosis

To discover the nature or cause of an illness by a medical examination.

Donor

A *donor* is someone who has a good match to your blood type for a blood cell transfusion. A *donor* may also be someone who is a good match to share their healthy bone marrow. A bone marrow *donor* can be a brother, sister or a parent, even someone you don't know.

Hope

The feeling that something will happen the way you want it to. *Hope* gives us all strength to deal with difficult situations.

Isolation

Isolation is a very clean environment, it helps reduce the chance of infection. A doctor will put us into *isolation* to keep us away from germs and other people who may be ill.

Neutrophils

A very important type of white blood cell. They protect the body against bacterial and fungal infections. *Neutrophils* are formed in the bone marrow.

Radiation treatment

A very strong X-ray that prevents bad cells from growing and destroys cancer cells. *Radiation* may also be given to a patient before a bone marrow transplant to allow better acceptance of the donated bone marrow cells.

Red blood cells

Red blood cells carry oxygen from our lungs through our body.

Special powers

Something you feel inside that makes you stronger. See *Bravery*.

Stem cells

Stem cells are found in the bone marrow. They are young cells that make other blood cells that grow up and are useful.

White blood cells

White blood cells fight infection. They protect against illness and disease.

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An aplastic anemia journey—from diagnosis,
through treatment and recovery.
With the support of people around him,
a child discovers his ‘special powers’
and that **“it’s in me to win”**.

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ISBN 978-1-7775464-0-3

