

ZAC'S PLAY DAY



Created for the spinal muscular atrophy (SMA) community

Illustrated by Charles Santoso





Spinal muscular atrophy (SMA) is a rare genetic disease that affects the nerves that control muscle, impacting the motor function of tens of thousands of people globally.

Some people with SMA are unable to sit, while others have difficulty walking. Some people have issues breathing, eating, and performing other daily functions. SMA can impact infants, children, teenagers, and adults—and each may experience the severity of the disease in different ways. SMA does not affect an individual’s ability to learn.

Zac’s Play Day represents an experience related to a child living with SMA, and it is not meant to represent the experience of everyone living with SMA.

The purpose of this story is to aid in the education and awareness of SMA—to help explain the reality of life with the disease, including both the limitations and possibilities individuals may experience.

We proudly dedicate this story to those with SMA, their families, caregivers, medical professionals, and SMA advocacy groups globally.

#zacsplayday #strongheartsstrongminds

About the Contributors

Zac's Play Day is brought to you by Biogen, in collaboration with the advocacy organizations Cure SMA and SMA Europe, and SMA experts Dr Robert Graham and Dr Crystal Proud. Many thanks to those who helped develop the content of this book and for their shared commitment to the SMA community. For more information about SMA, please visit www.TogetherinSMA.com, www.CureSMA.com, and www.SMA-europe.eu.



About the Illustrator

Charles Santoso loves drawing little things in his little journal and dreaming about wondrous stories. He gathers inspiration from his childhood memories, and curiosities he discovers in his everyday travels. He lives and works in Sydney, Australia. You can visit him at CharlesSantoso.com.

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“Rise and shine, my boys!” Zac’s mom shouted from down the hall.

Zac opened his eyes to a bright, new day. As he lay waiting for his mom to lift him up, he watched as his older brother Ziggy leapt out of bed and trampled around the room getting ready. Today, his brother was taking him to the playground.

Mrs. Zebra gave a hearty bray when she entered the room and saw the shirt Ziggy had put on. “Honey, what have I told you about wearing spots with stripes?!” she laughed.



She scooped her hooves under Zac's back and helped him into his wheelchair.

She then grabbed a fresh pair of socks and pulled them on for him.



“Let’s not forget to fluff your mane,” she said with a smile.

“Let’s do a mohawk today, Mom!” Zac bellowed as Mrs. Zebra ran a brush through his hair.



“Eat up, my loves!” Zac’s mom called out. “You don’t want to miss the herd!”



Zac may have been in a wheelchair, but he was pretty sure he could beat half of the pack with determination.





Before he knew it, he was the first to reach the gate.

Zac and Ziggy liked to play hide and seek together.
But today, they wanted to do something new.

Zac wondered if they should join the elephants
swapping trading cards, the animals playing tag
in circles around the fountain, or the group of
gazelles playing the latest video game.



Zac felt a tap on his shoulder.
He turned his head to see the belly
of a giant giraffe next to him.

“Did you hurt yourself?” the giraffe
asked from up high, gesturing
toward Zac’s wheelchair.

“I understand! I had my own
accident last week,” he said,
as he pointed to his neck.

“Actually, I’m not hurt,”
Zac said. “I have SMA.”

“S-M-what?” the
giraffe questioned.



Zac noticed several other animals approaching him and Ziggy, and they all looked as curious as the giraffe did.

Ziggy gave Zac a nod of encouragement as he cleared his throat and confidently said to the group that was quickly forming: "I have spinal muscular atrophy."

"What does that mean?" asked the ostrich.
Zac looked around to the group.





“It’s actually pretty rare.

And it means my body develops differently than everyone else’s.



Usually muscles get stronger over time, but with SMA, they get weaker.”



“How did you get it?” the elephant asked. “I was born with SMA,” answered Zac. “When I was a baby, my parents noticed I was a bit weak. It took me longer to sit up and my legs weren’t very strong, so they took me to the doctor, who told them I had SMA.”

“Does everyone with SMA use a wheelchair?” the hippo asked.



Zac thought about his other friends with SMA, Ping and Oliver. “No, not always,” he answered. “SMA is different for different individuals. Some are older, some are younger, and some need more help moving than others.”



“We sometimes need help with other things too, and for this, there are gadgets and gizmos,” Zac continued, “like a special tube that can help deliver food, or machines to help with breathing and coughing.”

A large group had gathered around Zac and Ziggy by now, all listening closely. Zac puffed up with pride as he continued to share his story.





“I even have a special team,” he said. “I call them my SMA Squad. There’s a doctor who checks my muscles and nerves. Another squad member who stretches my body so it stays flexible. One more to make sure I have a proper diet. And I also have a breathing doctor who keeps the muscles around my lungs as healthy as possible.”



Just then the animals heard a commotion
on the other side of the playground.

“Our ball!” shouted the meerkats.

One by one, all of the hopping animals
took turns trying to get the ball down.
The frog went first...not even close.



The gazelle got a running start
and sprung into the air. No luck.

Heads turned to the giraffe. "Sorry friends, I can't help, doctor's orders!"



“Don’t worry, we got this,” said the elephant, as he put his trunk to the ground and the meerkat climbed on.

He sent his long nose as high as he could toward the ball.

Even with the meerkat’s outstretched arm, they were still a few inches short.



Everyone was so busy looking up, that no one saw Zac zip around to the far side of the fountain. He had an idea.



Suddenly the water dropped to the ground
and the ball rolled to a stop.



All the animals looked up, surprised to see Zac's
hand on the fountain's OFF switch. He was smiling.

“When you have SMA, you use the strongest body
part you've got...your brain!” The animals cheered.



The elephant wobbled over to Zac: “A bunch of us are heading to the watering hole after this. You want to come?”





Helpful SMA terminology

BiPAP (Bilevel positive airway pressure): helps keep the lungs open and healthy by providing 2 levels of positive airway pressure delivered via a mask. The machine delivers a higher pressure and increased volume when someone inhales. On exhalation, the machine lowers the pressure to allow for a more normal breathing pattern.

Cough assist device: helps to clear secretions from the lungs. On inhale, air is pushed into the lungs to help them expand. On exhale, the machine creates a sucking force that pulls air out of the lungs and helps make the cough stronger and more effective.

Genetic disease: a condition that is caused by a change in the DNA of an individual. Most genetic disorders are rare and affect one person in several thousands or millions.

G-tube (Gastrostomy tube): a G-tube delivers liquid feedings directly to the stomach via a tube inserted through the abdomen. It is inserted during a brief surgical procedure and allows people with feeding problems to maintain proper nutrition, fluids, and medication.



SMA specialists

Neurologist: often the first doctor to meet with those suspected of having SMA. They specialize in the diagnosis and treatment of disorders of the nervous system (brain, spinal cord, nerves, muscles).

Nutritionist: important team member for individuals with SMA to support appropriate nutrition guidance and growth, as they may experience over- or undernourishment, which can affect bone strength, growth, and overall mobility.

Orthopedist: specializes in the surgical and nonsurgical treatment of conditions of the bones, joints, and soft tissue. Individuals with SMA may be at risk of certain orthopedic issues for which an orthopedist may recommend postural support (bracing) or surgery.

Physical therapist/Physiatrist/Occupational therapist: will evaluate an individual's range of motion, muscle strength, and mobility to assess need for stretching and strength training in SMA. They can also recommend exercises or assistive devices to help an individual maintain the best posture for breathing and eating.

Pulmonologist/Respirologist/Intensivist: doctors with specific expertise in the treatment of diseases of the lungs and the management of breathing disorders that may require medicines or specialized equipment to support.





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