



No Time For The Moon



By
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Illustrated by
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No Time for the Moon

Possibility begins in the imagination

No parent imagines that their child will suddenly become weak or limp mid-pirouette or running down the field. As a child is evaluated and diagnosed with acute flaccid myelitis (AFM), we seek information, tools, support, and especially ways to guide our child through this unknown realm.

No Time for the Moon invites you and your child to imagine and to hope.

This picture book, written for ages five and up, aims to be a useful conversation starter for children of all ages.

You might want to read this book first to yourself and take a look at the guide in the back, where you will find answers to frequently asked questions and a list of resources. Then invite your child to join you in this adventure to the moon.

Possibility begins in the imagination, and imagination is not stopped by AFM.

—Diane Roston, MD

“We dedicate this story to children and families who have advocated tirelessly to improve AFM awareness and understanding. We appreciate their resilience and commitment, and work hard each and every day to do our part to support them and their cause.”

— The Centers for Disease Control and Prevention (CDC)

“To the children and families of our community, this story was written for you, with you, and always with you in mind. Whatever your diagnosis, or when or how it impacted you and your family-we see you, hear you, know you, and love you. We share your grief, heartache, healing, hopes, and dreams as we journey the unknowns together, imagine the possibilities, and strive to achieve them.”

— The Siegel Rare Neuroimmune Association (SRNA)

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No Time
For The
Moon

**Can you spot a furry Wouldya in the tree?
—sitting upside down and downside up
playing nonstop-ily.**

What is a Wouldya, anyway—?

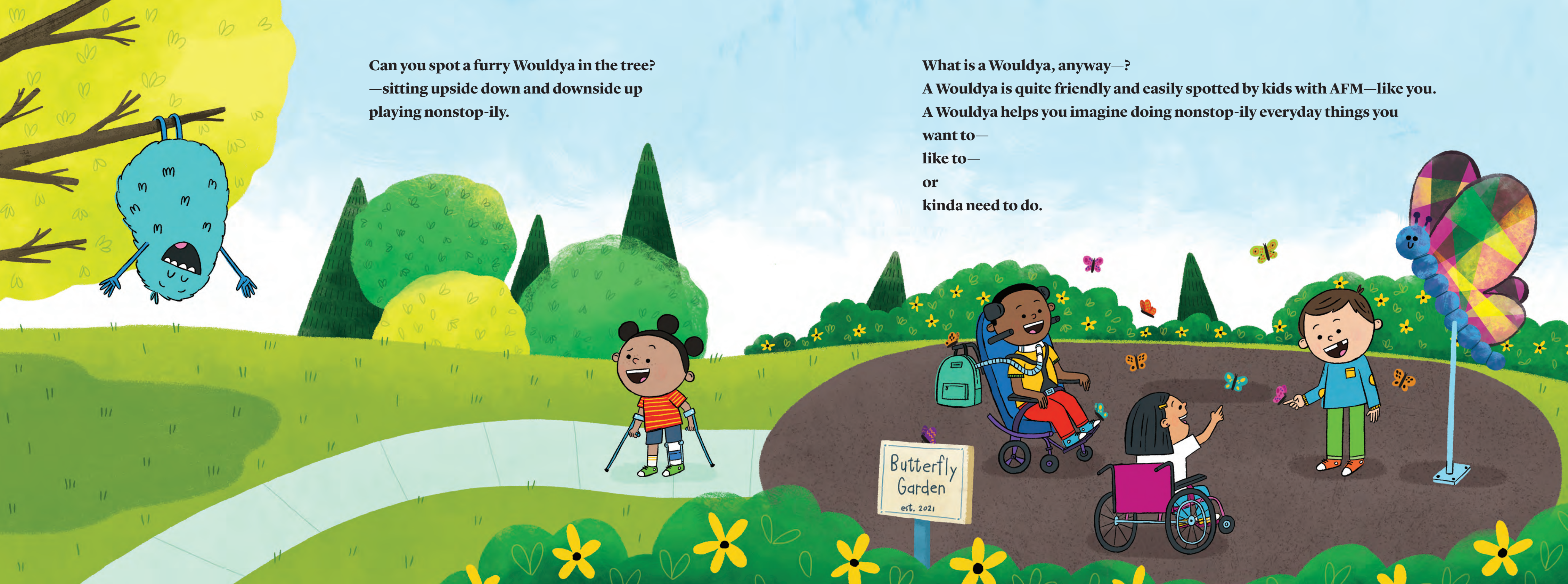
A Wouldya is quite friendly and easily spotted by kids with AFM—like you.

**A Wouldya helps you imagine doing nonstop-ily everyday things you
want to—**

like to—

or

kinda need to do.



When you first meet a Wouldya, what would a Wouldya say?

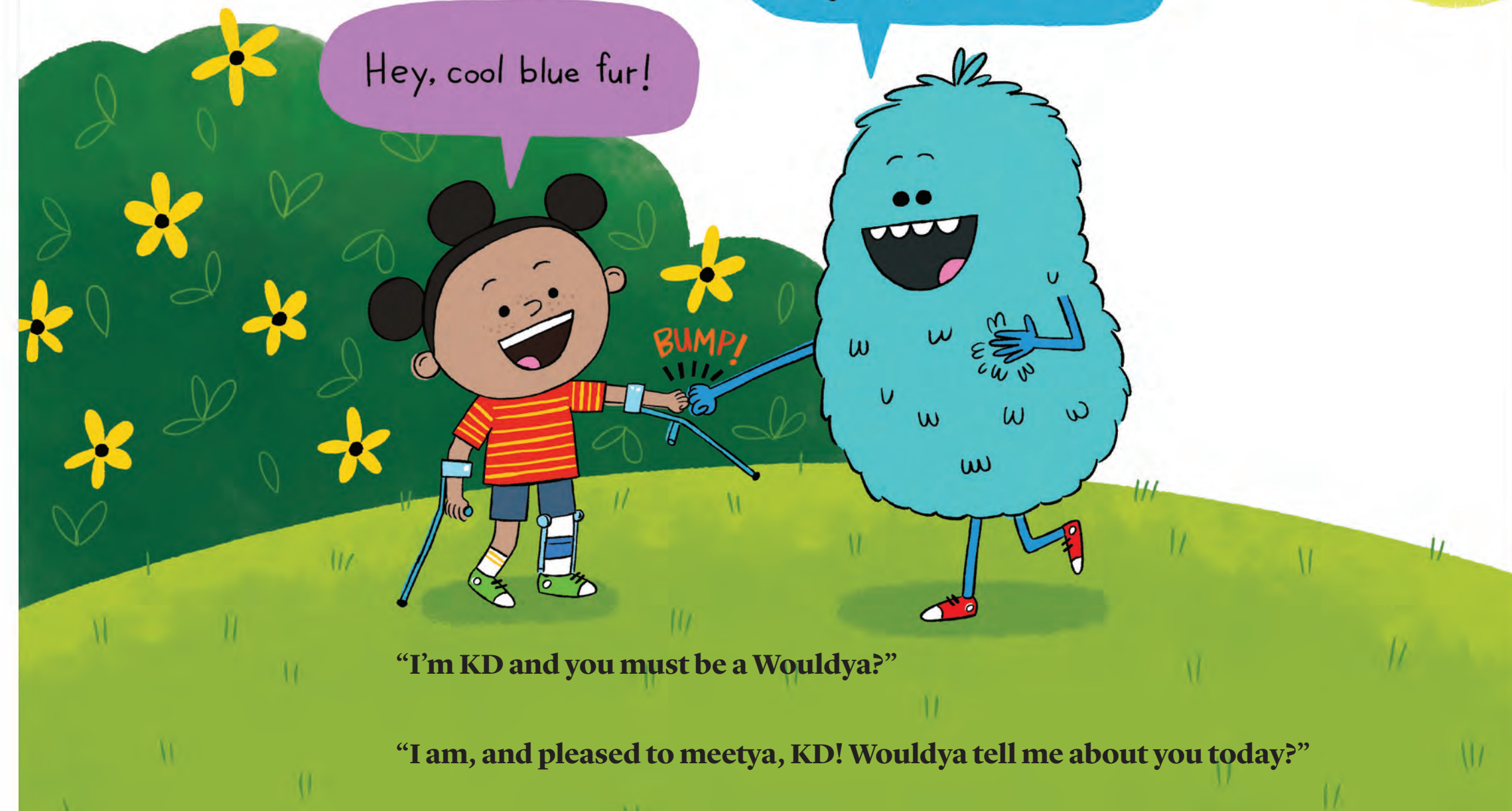
Well, a Wouldya would say ...

I'm a Wouldya and wouldya
tell me about you today?



Hey, cool blue fur!

Thanks!
I just got a fur cut.



"I'm KD and you must be a Wouldya?"

"I am, and pleased to meetya, KD! Wouldya tell me about you today?"



Here's stuff about me today—
drum roll please!



1 I am a good friend.

2 I like sports and being with my friends.

3 I love to read everything including the backs of cereal boxes.

4 I have AFM which to me means **A**wsome, **F**ierce and **M**otivated!

5 I think it's good to know that there are other kids like me who have AFM.



My Superpower!



My smile. A smile goes a long way. I keep a positive attitude.



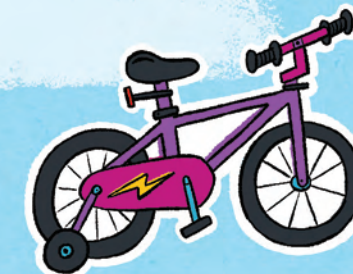
I have AFM

I can't explain it that well. My mom can. I was really young when I got it. Doctors think AFM comes from a virus that doesn't get along too well with my spinal cord in my back. They keep learning new stuff about AFM, which is very cool!



I learned

There are a lot of fun things I can do when I'm wearing my brace. It does stink sometimes, but then I talk to people about my feelings or just get busy doing stuff. I get fitted for a new brace every two years because it needs to grow with me and my leg is getting stronger. I'm learning to ride a bike!



What I say to myself

Good things come from hard things. I think on the bright side, like when I'm in the hospital or at the doctor or doing stuff I don't want to. I think that tomorrow this is all going to be over—and we usually do something fun after! So, just remember that the bad stuff doesn't last forever and there's always good stuff to come!



What I bring with me to hospital or doctor visits

My stuffed lion, Gadget. My little brother comes with me. Sometimes he gets restless because I get all of the attention. But he brings books and games and he gets the good snacks afterward, too.



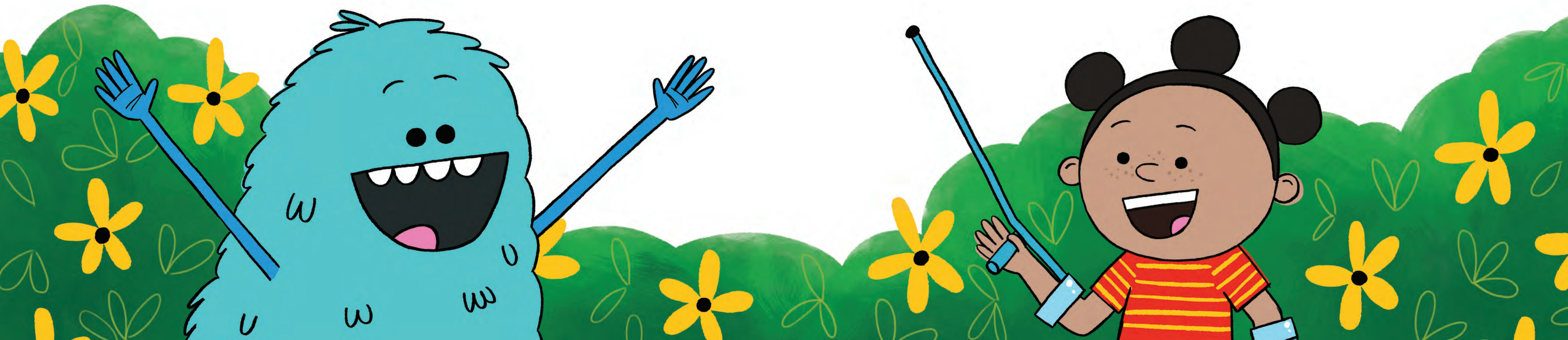
**“Thanks for sharing this cool stuff about you, KD!
What wouldya imagine doing today?”**

**“Wouldya learn the guitar, play sled hockey or dye your hair blue,
Build a computer, look for frogs or design your own fake tattoo?
Wouldya follow your imagination to do stuff in a new way—
Would that new way be something wouldya try today?”**

“Yup! All sounds good but I would dye my hair **orange and—
I would like to try sled hockey today!
Oh, and there’s one more thing not on the list—”**

“What’s that?”

“I would like to be the first kid on the moon!”



“Okay,” says the Wouldya, “but I’m forgetting something—”

“It’s my Wouldya bag. I take it everywhere—
unless I forget, and then it finds me and the kid who would need it!”

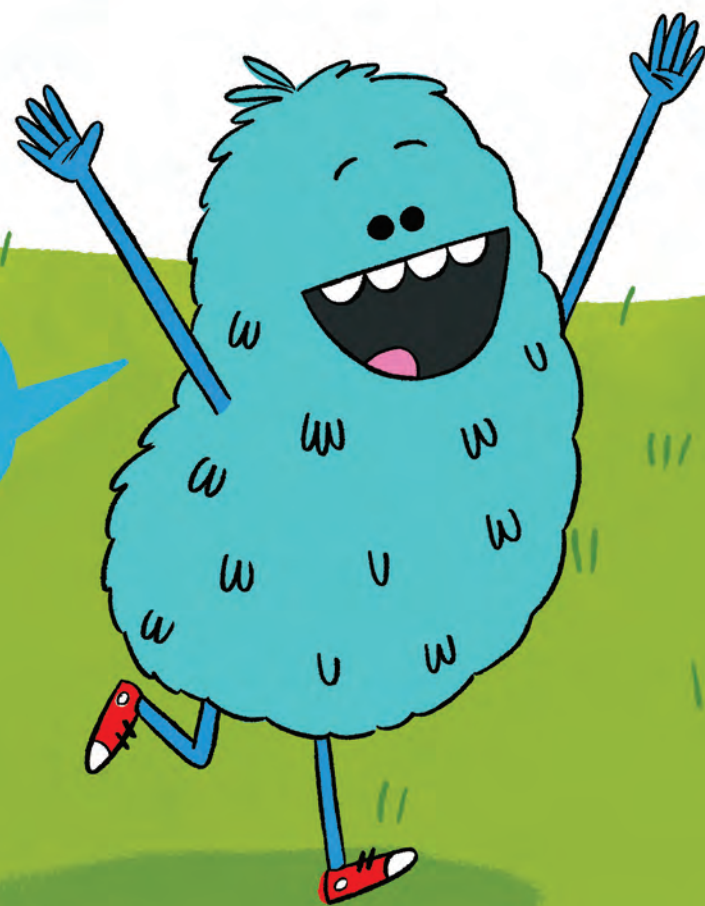
“What do you have in there?”

“Well, it depends on what someone would want to,
like to or kinda need to do.”

“Maybe there’s something in there for me?”

Yes! Everything you will
need for sled hockey.*

*Known as sledge hockey in Canada.





What other stuff do you have in there?

Well, depends on what Someone would want to, like to or kinda need to do.

“Maybe there’s something in there for me?”

“There sure is,” says the Wouldya. “And, wouldya tell me about you today?”



I’m Koa.

Nice to meetya, Koa!



And, here's stuff about me today—
cue the drum roll please!

1 I am on a dance crew with my friends.

3 I love to write stories and plays.

4 I have AFM and go to a camp
each summer to meet and hang out
with other kids who have AFM like me
and we stay in touch.

2 I like being independent.
Sometimes I get frustrated
when I need help doing stuff.

5 I think I could teach other
kids how to dance no matter
how they can move.



I learned

I can be in my dance group like I was before I got AFM. I do a lot of my dance moves in a new way, and I like how they look! I can keyboard with some fingers on my right hand so I can write my stories and plays that way.



What I say to myself

"I can do it!" When I was first in the hospital, it was hard for me to move my body at all. I kept thinking I would find a way to get back to dancing. It was hard but I did it. Sometimes I wish I didn't have to ask for help like when I get dressed or put on my backpack. Being independent is important to me.

My Superpower!



Is that I have AFM. I get to do and see a lot of things. The world just opened up and I'm meeting people and traveling to cities where my doctors are. My heart is bigger now for other people.

I have AFM

It is different for each kid. For me, I cannot move my left hand and my right hand and shoulders are weak. I work hard with my physical therapist, who helps me exercise my body to get stronger. I also work with my occupational therapist, who helps me learn how to do everyday stuff in a new way—like brush my teeth or comb my hair. Some of my shirts have magnets instead of buttons so it's easier for me to get dressed.



What I bring with me to hospital or doctor visits

Video games. I ask my dads to have my favorite candy around for after. We do a lot of fun stuff like get ice cream and that's the favorite part for my two sisters, too!



**“Thanks for sharing this cool stuff about you, Koa!
What wouldya imagine doing today?”**

**“Wouldya want to write a story or a play or dye your hair blue,
Read a book, take a dance class or visit the zoo?
Wouldya follow your imagination to do stuff in a new way—
And would that new way be something wouldya try today?”**

“Yup! All sounds good but I would dye my hair **purple and—
I would like to write a play about kids like me!
Oh, and there’s one more thing not on the list—”**

“What’s that?”

“I would like to be the first kid on the moon!”



“This bag has something for you, Koa.” the Wouldya says.
Here’s some cool stuff to help you work on your play!



“What other stuff do you have in there?
I’m Kiva and maybe there’s something for me?”

“Sure is,” says the Wouldya.
“What wouldya like to tell me about you today?”





Here's stuff about me today—
start the drum roll please!



1 I am good at solving mysteries.

2 I like to do puzzles.

3 I love basketball!

4 I have AFM and I like to shoot
baskets with my brother.

5 I think I would be an astronaut and
set up the first basketball court on Mars!



My Superpower!



Is that when I wish I could do something, I set that as a goal. I work at it. Sometimes I get mad and have to step away or go to a private place and take a deep breath. Then, I come out again and keep practicing until I reach my goal.

I have
AFM



I got it when I was six months old. It can affect anywhere in your body; for me, it was in my legs. I go to occupational and physical therapies after school, and they help me a lot. I work hard when I am there—whew! I like getting stronger and am proud of myself.

I learned

That kids like us with AFM can change the world, like in—we can be amazing! We can make a difference. It's important to know that we can do a lot more than we think we can to reach our dreams! We can change the world one person at a time by doing what we can do best.



What I say to myself

Everybody has something they are trying to work on. I am being the best me that I can be, and I don't stop!



What I bring with me to hospital or doctor visits

My superhero cape, of course! Tons of books, too! Mom and Dad bring my little brother and we have fun snacks and adventures afterwards. One time we went to an amusement park and had cotton candy and pizza.



**“Thanks for sharing this cool stuff about you, Kiva!
What wouldya imagine doing today?”**

**“Wouldya create a science experiment, plant a garden or dye your hair blue,
Play wheelchair basketball or play songs on a kazoo?
Wouldya follow your imagination to do stuff in a new way—
And would that new way be something wouldya try today?”**

“Yup! All sounds good but I would dye my hair **pink and—
I would like to play wheelchair basketball and be on a team with other kids!
Oh, and there’s one more thing not on the list—”**

“What’s that?”

“I would like to be the first kid on the moon!”





“Hi, I’m Koro. Maybe there’s something in the bag for me?”

“There sure is,” says the Wouldya.

“And, Koro, wouldya tell me about you today?”





Here we go—my turn for the drum roll, please!

1 I am big into technology and learning code.

2 I like playing music with my friends and acting in plays.

3 I love being creative, and especially composing my own music.

4 I have AFM and for me it stands for A-flat major because that is the key my favorite composer, Beethoven, uses a lot!

5 I think all people are different from each other; everyone is different all of the time.

My Superpower!



Determination. That means I never give up when I decide to do something—I do it! I always see myself working hard and practicing whatever I am learning to make my future better. I am never going to quit.

I have AFM

A lot of people don't know what it is. I'm okay with telling people about AFM because it's part of who I am.



I learned

It's super important for me to set small goals. I feel good when I meet them. It is sometimes hard work or uncomfortable doing my PT and OT exercises but I keep doing them. I keep getting stronger!



What I say to myself

How can I make things better? Each day my goal is to be creative through the arts and to show others with physical challenges how the arts and being creative can be really fun and it helps your mood. With my mouth stick I compose music and play the piano.



What I bring with me to hospital or doctor visits

A picture of my dog, Rocket, and I always wear a new friendship bracelet that my friends give me when I go to the hospital. I have a whole collection! My parents take me to a play or concert afterward. My big sister comes, too!



**“Thanks for sharing this cool stuff about you, Koro!
What wouldya imagine doing today?”**

**“Wouldya want to write a song, design a video game or dye your hair blue,
Perform in a play, draw a picture or create a recipe for a veggie stew?
Wouldya follow your imagination to do stuff in a new way—
And would that new way be something wouldya try today?”**

“Yup! All sound good but I would dye my hair **green. I would like to
paint a picture of my dog today and act in Koa’s play when he’s finished!
Oh, and there’s one more thing that is not on the list—”**

“What’s that?”

“I would like to be the first kid on the moon!”



Here is something in the bag for you, Koro. I can't wait to see the drawings you make, and to see you act in Koa's play. I hope I can get a front row seat!

Thanks!
I'm going to start drawing Rocket right now!



“Do you know the one thing that all of you have in common?” asks the Wouldya.

“What?” KD, Koa, Kiva and Koro shout together.

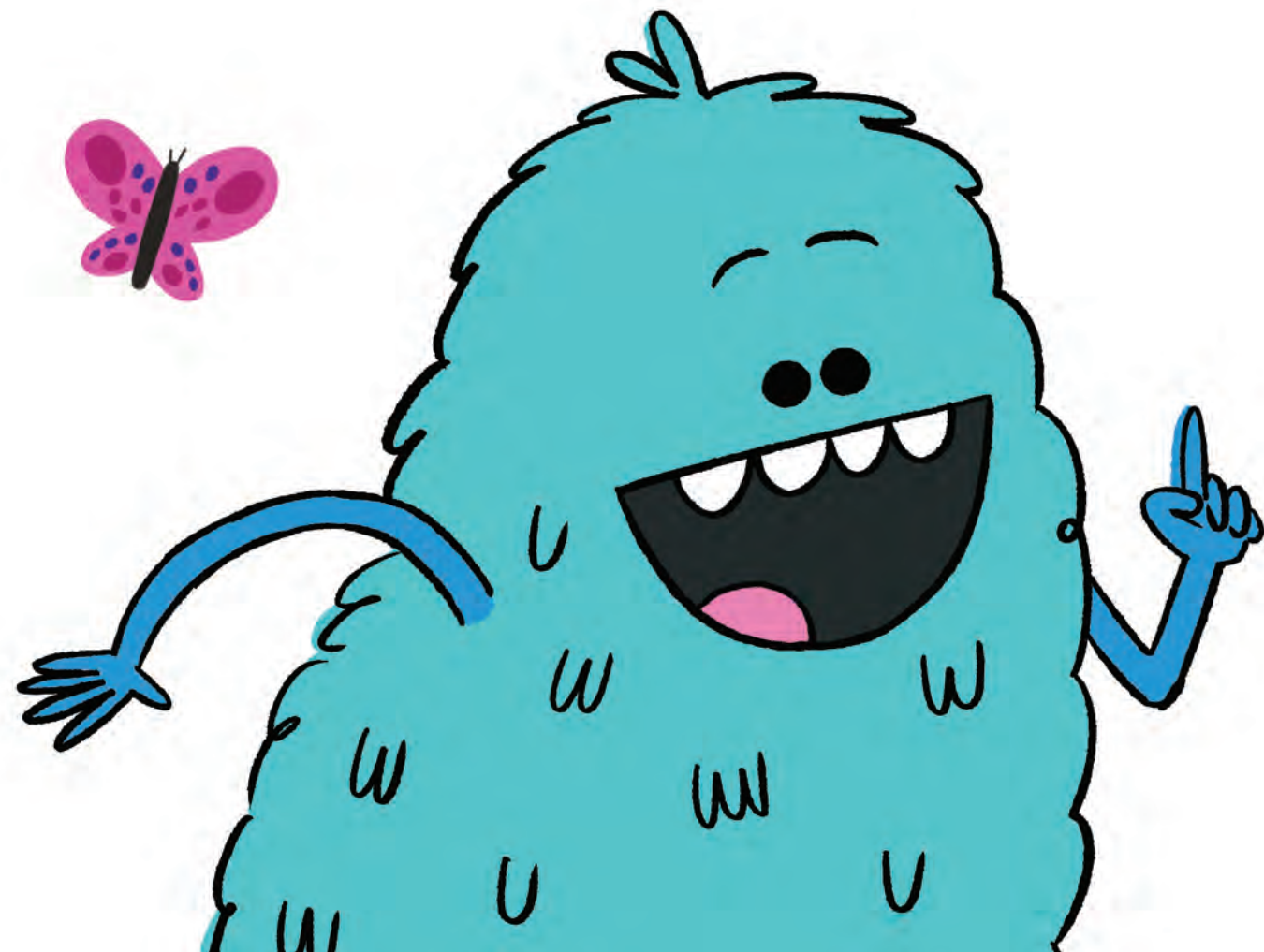
“You *all* want to be the first kid on the moon!”



“We *all* can’t be the first kid on the moon,” moans KD.

“I’ve got it!” says Koa. “We can be the first *kids* on the moon!”

“Yeah, we can *all* do it together!” Kiva shouts.



“We’ll need a name for our flight team,” adds Koro.

“I have an idea,” KD says. “How about the AFM Flight Team because we’re *awesome*, *fierce* and *motivated*. We can put that on our flag and on the spacecraft, too!”





I am working on a power source so we will be able to run our computers and I am also making our AFM flag!

I am developing a navigation system so we can aim right for the moon. And, yeah, also working on some lunar dance moves!



I am constructing the ramps to the launching site and a communication system so we can talk with Earth when we land on the moon!

I am designing the spacecraft – and working on a foolproof way to take space selfies!





Oh, I have my first sled hockey lesson this afternoon.

I have rehearsal with my dance crew.

I'm going to my first wheelchair basketball practice.

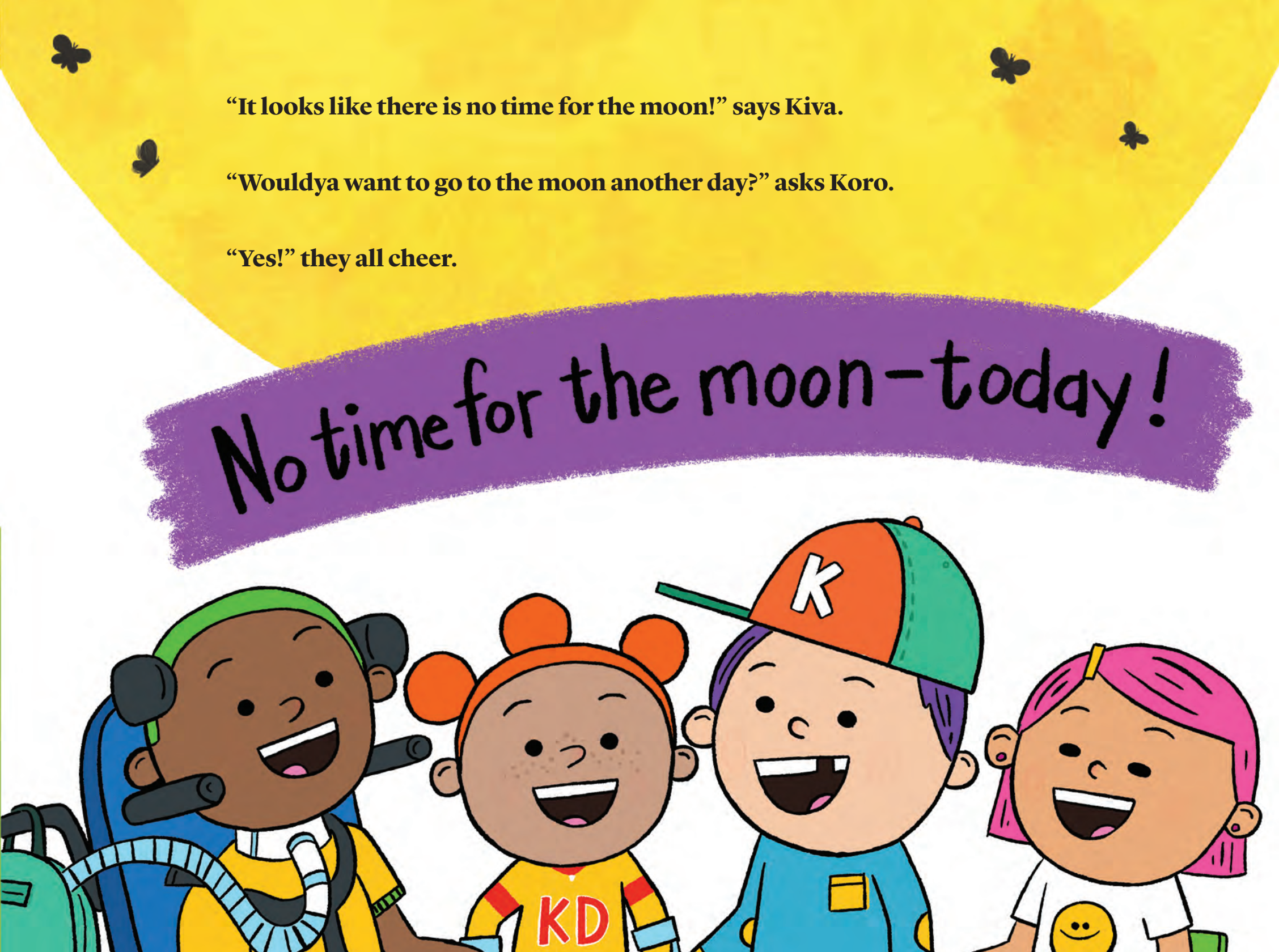
And I can't wait to take my first drawing class. It's this afternoon, too.

"It looks like there is no time for the moon!" says Kiva.

"Wouldya want to go to the moon another day?" asks Koro.

"Yes!" they all cheer.

No time for the moon—today!



AFM Guide for Grown-ups

By Diane Roston, MD

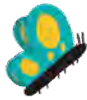
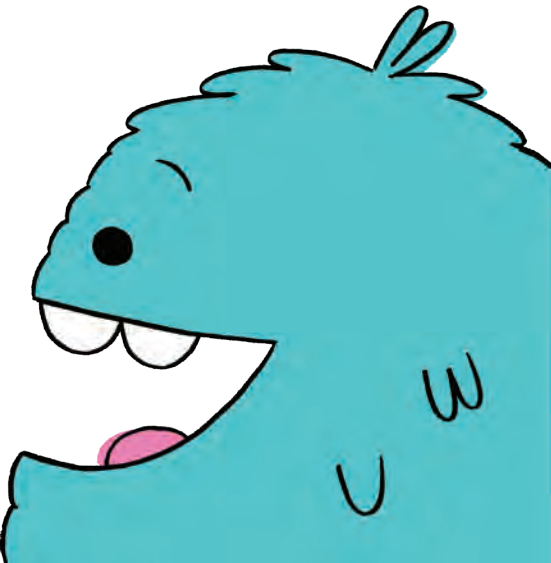
Although addressing parents, this guide serves any adult whose life is touched by a person with AFM.

The Journey Begins: Contemplation

“Use your imagination and you will find a Wouldya anywhere and everywhere,” we are told.

A Wouldya is the perfect furry friend to bring you and your child on an AFM journey together. In the beginning, you will want to contemplate with your child about what might happen, what is important to your child, and what worries them. Contemplation, a stage in psychologists James Prochaska and Carlo DeClemente’s theory of change,¹ is the first step toward adaptation and resilience, which are healthy responses to meeting life’s challenges. A Wouldya invites us to imagine “doing nonstop-ily everyday things you want to, like to, or kinda need to do.” Herein begins an invitation to talk with your child about what matters in their world, as well as what your child will need to know about AFM.

¹Prochaska and DeClemente, 1983, as cited in Prestwich et al., 2018. Prestwich, A., Kenworth, J., and Connor, M., (2018). Health Behavior Change: Theories, Methods and Interventions. Routledge Press.



Be direct with your child. Provide simple information at their level of questioning and development.

You might ask your child . . . What thoughts and feelings have you had about how you got AFM? What is this experience like for you? What questions do you want to ask about what is happening in your body? What are the activities, the friends, the dreams that are most important to you?

You might reflect with your child . . . You did not cause this condition to happen, no matter what you did or didn’t do. It’s okay to ask questions. It’s okay to feel scared or sad or however you feel. AFM is different for each person. You have a story to tell about your experience. You can teach others what you are learning. Those who love you will want to know. Those who teach you or help you will need to know.





Next step: Preparation

A Wouldya invites us to learn from our child. “I’m a Wouldya and wouldya tell me about you today?”

Prompts such as *I am . . . I like . . . I love . . . I have AFM . . . I think . . .* inspire us to remember that our child is more than just a medical condition. They have thoughts, feelings, passions, goals. The Wouldya reminds us that our child’s development continues even within the limitations of AFM.

We talk with our child about preparation for what might come next. The preparation process involves exploring options, resources, supports, as well as factoring in intangibles, such as motivation, effort, commitment, time considerations, financial realities.

You might already have a team of providers that may include a primary care provider, neurologist, rehabilitation medicine physician, physical therapist, occupational therapist, school personnel, mental health professional and others.



You might ask your child . . . What questions do you have about your treatment choices? What helps you get ready? Who is on your treatment team?

You might reflect with your child . . . You can ask questions and have an active voice. I will help you speak your thoughts and feelings if you need me to. If you and I don’t see eye to eye, we will talk over our wishes and concerns. Even when things don’t always go your way, you are the most important person on the team.



Strong Connections: The Importance of Family and Community

A Wouldya reminds you and your child that you are not alone. Other children on the world's playground have AFM.

A Wouldya brings AFM children together: “Do you know the one thing that all of you have in common?” asks the Wouldya. “You all want to be the first kid on the moon!”

Connecting with other kids with AFM for fun and friendship is central to many children’s AFM experiences.

The Wouldya also reminds us that AFM affects the whole family. KD, Koa, Kiva and Koro each speak about a brother or sister who comes to doctor visits or the hospital with them. Each AFM kid talks about their parent(s) being by their side.



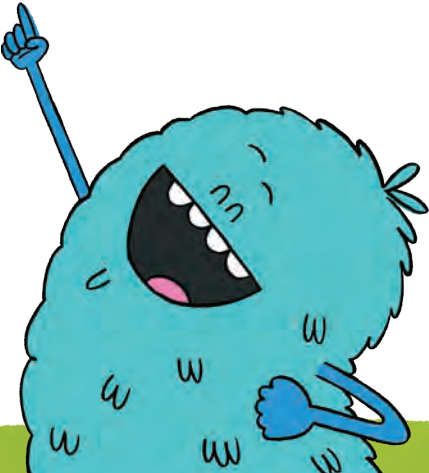
Finally: Action

Prochaska and DeClemente’s final stage of change is action.

The Wouldya challenges each child: “Wouldya follow your imagination to do stuff in a new way? Would that new way be something wouldya try today?”

Even as each child describes how AFM affects them, they also acknowledge their superpower and set their sights on intentions for today and for the future: sled hockey, dance rehearsals, wheelchair basketball, and art class.

The Wouldya reminds us of the importance of keeping hope alive and “aiming for the moon.”





You might ask your child . . . What do you want to work toward accomplishing? Who do you want to stay connected with? What matters so much to you that you are willing to work for it? What are the first steps? What supports will we put in place to help you?

You might reflect with your child . . . There will be obstacles in the path—there always are—including obstacles put there by symptoms of AFM. Yet with intention, you can strive to achieve what you set out to do.



Elisabeth Kubler-Ross deepened our understanding of adaptation to loss when she described stages of grief to include denial, anger, bargaining, depression, and acceptance. The order isn't necessarily linear or tidy, as Kubler-Ross had initially proposed, but the journey takes us in the end to acceptance of what we cannot change.

You help your child to grieve the loss of muscle strength, mobility or function, even as you encourage them to go for their dreams.





You might reassure your child . . . I am here to support you and help you grow. We are in this together and we are not alone. There are others all over the world on this journey with us.



There is always hope for improvement, and we set our sights on the moon, reflecting a shift into the stage of action, of setting intentions and taking steps.

The Wouldya would want us to remember that children with AFM grow up to be teachers, scientists, dancers, artists, engineers and Paralympians.

As KD says, AFM stands for “Awesome, Fierce and Motivated!”

Perhaps someday children with AFM will be the first kids to land on the moon.

But there is “no time for the moon—*today!*”



AFM Frequently Asked Questions

In those first moments when a child's limb doesn't move or their facial muscles droop, a child looks to the grown-up to explain. We educate ourselves so we can guide our child.

What in the world is acute flaccid myelitis (AFM)?

Acute: sudden onset;

Flaccid: decreased or absent muscle tone;

Myelitis: inflammation of the spinal cord, the part of the central nervous system that sends messages between the brain and the body, in this case, to nerves that control muscles and reflexes.

AFM is an uncommon neurologic condition that affects the motor nerves in the spinal cord that control muscle function. AFM affects the muscles that move the neck, shoulders, hips, and trunk more than the muscles of the fingers and toes. Muscle weakness usually happens on one side of the body, but sometimes both sides of the body can be affected. Facial muscles and breathing muscles can also be impacted.

How is AFM diagnosed?

AFM is diagnosed based on detailed information about a child's medical history (such as any recent illness) and results of a thorough neurologic exam, MRI scan of the spinal cord and brain, and lab tests.

Most children with AFM had a fever or cold-like symptoms before their muscle weakness started. The neurologic exam would show decreased muscle tone and weakness, and often absent reflexes. MRI would show abnormalities in the gray matter of the spinal cord where many motor nerves are located. Nerve conduction studies and EMG (electromyography) can help with the diagnosis and prognosis.

AFM can look like other neurologic conditions, and the MRI and laboratory testing can help eliminate other possible diagnoses. Because AFM is uncommon, most primary care doctors might not have experience diagnosing or managing AFM, so it's important to have a neurologic or infectious disease doctor on the medical team.

Who gets AFM, and what causes it?

There are still many unanswered questions, but we have learned a lot since the first cases in 2014. AFM mostly affects school-aged children, but sometimes infants and adults can have AFM. Most patients developed AFM between August and November. Increases in cases occurred nationally in 2014, 2016, and 2018. AFM can be caused by several viruses, including enteroviruses such as EV-D68, which are likely the cause of the increases in cases. Enteroviruses are common during late summer and fall, and usually cause mild illness, like the common cold.

Scientists are still trying to understand why some people get AFM, while most others don't. They are also trying to figure out if the spinal cord damage is caused by the virus itself, the immune system's response to the viral infection, or a combination of both. Answers to these questions will help with finding new therapies and potential prevention measures.

What is the treatment for AFM?

The Food and Drug Administration (FDA) has not yet approved any treatment for AFM. Ask your child's medical team about treatment options that have been used and might be appropriate for your child, including intravenous immunoglobulin (IVIG), steroids, and therapeutic plasma exchange (TPE). After the acute illness, nerve or tendon transfers can be helpful for some children. There are other important interventions, such as physical and occupational therapy, that should be started right away and will be a key part of your child's rehabilitation journey. In addition, other therapies such as music, art, play, speech, and nutrition are often extremely helpful. Because your child is unique, the treatment plan should be tailored to your child's needs.

What is the prognosis for AFM?

We know that nerves heal, and we know that nerves heal slowly. People with AFM continue to improve their strength and functional capabilities months to years after their acute illness. Your child's recovery is going to be as individual as your child.

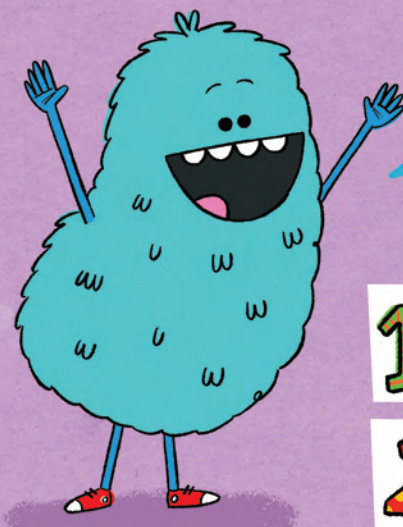
Because AFM affects the motor neurons in the spinal cord, AFM does not affect intelligence, emotional capacity, interpersonal connection, personality, or imagination.



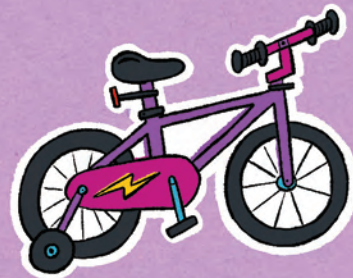
A Template for Further Exploration

The template on the next page is directed to respond to the same template prompts that KD, Koa, Kiva and Koro did. It's a fun way to keep an ongoing record or check-in of thoughts and feelings, as a start of a journal or as a guide for conversation. This page can be photocopied and is available as a download on SRNA's website at srna.ngo/explore.





I'm a wouldya, and wouldya tell me about you today?



1 I am

2 I like

3 I love

4 I have AFM

5 I think

My Superpower!



I have
AFM

I learned



What I say to myself



My goal today



What I bring with me to hospital or doctor visits



My goal this week



Eric Arnold is a children's author originally from Cleveland, Ohio, and now living in the Boston area, although he remains loyal to Cleveland sports teams. Inspired by his experience as a teacher, his books ignite imagination on many subjects: volcanoes, sports, biography, space travel, humor and books for the *Star Wars* movies. For fun, Eric seeks travel adventures and looks for a Wouldya wherever he goes.

Diane Roston, MD, is on the clinical faculty at the Geisel School of Medicine at Dartmouth and serves as Medical Director at West Central Behavioral Health in Lebanon, NH. She wears many hats: Writer. Doctor. Mother. When not admiring squirrels doing flips onto her bird feeder, she enjoys reading, learning new stuff, hiking in the White Mountains, and, of course, chocolate.

Daniel Wiseman is a NY Times best selling illustrator of several books for children. He lives in Knoxville, Tennessee with his lovely wife, two beautiful sons, one shaggy dog, and an elusive hamster. When he's not writing or drawing he enjoys hiking in the mountains, wading in creeks, and every once in a while taking a nap.

For additional information and resources for children, families, and clinicians about acute flaccid myelitis (AFM), please visit cdc.gov/afm and srna.ngo

What is a *Wouldya*, anyway—?

A *Wouldya* is quite friendly and easily spotted by kids with AFM—like you.

A *Wouldya* helps you imagine doing nonstop-ily everyday things you
want to—
like to—
or kinda need to do.

Meet KD, Koa, Kiva and Koro! When these friends spot a *Wouldya*, their adventures take off.

Be sure to look up, down and sideways to spot a *Wouldya* where you live. And let your adventures begin!

No Time for the Moon is a children's book about four friends from the acute flaccid myelitis (AFM) community who meet a *Wouldya*, a magical furry creature, and begin a fun journey of self-discovery, exploration and adventure. With delightful illustrations along with informative and interactive materials, children learn about their condition with guidance and support from adults.

The AFM Guide for Grown-ups and AFM Frequently Asked Questions sections provide resources for parents, family members, caregivers, school personnel and clinicians to help ease the rehabilitative journeys of children with AFM.

