WHAT IS MITOCHONDRIAL DISEASE?

Mrs. Nebel’s and Ms. Springer’s Fourth Grade Class
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Dedicated to

our classmate, Jorja
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Why We Want to Help

This is why we want to help because we have a classmate that has Mito, and we are concerned about her health. So we are donating stuff like canvases, coloring books, and things children can play with at the Children’s Hospital.

Many people don’t know what Mito is like. Mito is short for Mitochondrial Disease, which you should know Mito is a disease. Mito is a disease that can be really bad or not as bad. When people get Mito, they might use some tools such as G-tubes and pumps. They also take vitamins and supplements. Some people call these Mito Cocktails! Some people with Mito have
service dogs that wear special vests. Most kids with Mito get dizzy, headaches, and body pain. Some people with Mito need to eat things with lots of sugar so they have lots of power. They might eat things such as peanut butter and candy. Since many people don’t know a lot about Mito, we wrote this book, so we can raise awareness about Mitochondrial Disease!
Today we will be talking about Mitochondrial Disease. Mitochondrial Disease is a disease that forms in your mitochondria, which is a part of your cell. Mitochondrial Disease is very rare and when you get it, it is very easy to not have a lot of energy.

Now we will be talking about the symptoms of Mitochondrial Disease. The muscular symptoms are muscle weakness and problems with coordination. Also, there can be loss of muscle. Now we are going to be talking
about the symptoms of the body. Some are not having a working nervous system, being tired, or not being able to exercise. The majority of kids go to school, but the others may be homebound.

There is no cure to Mitochondrial Disease yet. When you have Mitochondrial Disease, you might have eye weakness. Some other common symptoms may be trouble learning, seizures, and weight loss. Only about 20,000 Americans have Mitochondrial Disease.
Living with Mitochondrial Disease: Our Classmate Jorja

Jorja has played many sports like track, cheerleading, and gymnastics. She likes to eat, go outside, and play with her friends. Jorja has two rare diseases called Mito and HLH. HLH stands for Hemophagocytic Lymphohistiocytosis. They have no cures. Jorja’s favorite book series is Dork Diaries. Her favorite things to eat are mac and cheese, spaghetti, peanut butter, and pb&j.

She was born sick, but she started getting answers in 2012 when she was about four. She is in the hospital a lot, and when she’s in the hospital, she likes
to paint ceiling tiles and her dad’s fingernails. She also has occasional seizures. When she has seizures, she cannot see or hear, and it lasts about two minutes, but once it lasted for two hours. She has had a wheelchair ever since second grade, but she says she would rather have her dad carry her than use it. She wears a mask during sick season to help protect her from germs.
Thirty-five year old Rocco Baldelli has Mitochondrial Disease! Rocco was born on September 25, 1981 in Woonsocket, Rhode Island. He went to high school at Bishop Hendricken in Warwick, Rhode Island. Rocco was diagnosed with Mitochondrial Disease when he was twenty-nine. In baseball, Rocco made over six million dollars in his career. Baldelli had the privilege of being asked to be the Rays new base coach and the former top prospect.
In 2005, Rocco did not play in major or minor leagues because he was
injured. The total number of homeruns he hit was sixty. During the 2007 season, his legs would tighten up and cramp while he was playing. Before retiring from baseball, Rocco made it to the World Series. Rocco retired from baseball when he was twenty-nine. His last baseball game was on October 3, 2010. Even though Rocco Baldelli had Mitochondrial Disease, it didn’t stop him from having a great life!
Poem

Mighty Mito is not fun.
Mighty Mito does not get things done.
I can’t always play.
I have to stay,
even on the finest day.
Some days are fun,
when I have the energy to run.
Some days are sad,
when I just feel really bad.
Even though I sometimes cannot run,
I always end up having fun!
A Short Story

My name is Lilly, and I have Mitochondrial Disease. I’ve had it since I was really little. I have a service dog, too! His name is Benny, and he always keep me company and safe. Mitochondria is something in your body that makes energy, but some mitochondria do not work in some kids. I’m one of those kids!
I love you, Benny!
I get stomachaches, leg cramps, and headaches, and I get really tired sometimes. My friend Billy comes over and plays with me when I have some energy. Sometimes, I even go to his baseball games!

Yes, Mitochondrial Disease may make me tired, but that doesn’t mean that I can’t have fun! One time I went to school for a whole week! I had so much fun with my friends, just like I always do!
Games

Our class created different games for kids to play!
Blimp It

Objective:
Own the most continents

Directions:
Imagine you are riding on a blimp traveling throughout the world. Start on the blue dot. Roll the dice. Your goal is to land on a continent (red dot). When you land on a continent, guess the name of the continent. If you guess the name right, you get to “own” that continent. Whoever gets the most continents wins.
21 Game

Objective:
Try not to say 21

Directions:
You count from 1-21, but you can only say up to three numbers at one time. You don’t have to say the same amount of numbers.

Example:
Ian: 1, 2  
Jacob: 3, 4  
Ian: 5  
Jacob: 6, 7, 8  
Ian: 9, 10  
Jacob: 11  
Ian: 12, 13  
Jacob: 14  
Ian: 15, 16  
Jacob: 17, 18, 19  
Ian: 20  
Jacob: 21  

*Ian won, and Jacob lost.*
Tap

Objective:
Guess who tapped you

Directions:
One person sits in the middle of a small circle of people and closes his or her eyes. Another person taps the person in the middle. The person in the middle has to guess who tapped them.
Back to Back

Objective:
Get to the end of the finish line first

Directions:
Back to Back is where two players/pieces start with the back of each piece together. Roll the dice and move that number away from each other. The first person who gets to the end of the line first wins.
Jumper

Objective:
Jump the farthest

Directions:
First get four yard sticks (or something to measure). Put the yard sticks in a line. Then jump. You get points based on how many inches you jump. One inch equals one point. Whoever jumps the farthest wins.
1-2-3-4 Hand Game

Directions:
Use the “Miss Sue” hand movements. (One hand up, the other hand down. Repeat with other hands. Clap each other’s hands. Clap your hands one time.) You can also make up your own hand movements.

Lyrics:
1-2-3-4
Please go out the door.
5-6-7-8
Please don’t come home late.
9-10
Let’s go do it again.