For Kids, By Kids

JUST FOR KIDS: THIS THING CALLED LEUKODYSTROPHY

Hunter's Hope
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Hi,

Do you have leukodystrophy or maybe one of your siblings does? Does your friend or neighbor have leukodystrophy or someone else you care about? Maybe you are interested in supporting leukodystrophy. Hey, us too and this book is for you!

Remember every kid is different and every leukodystrophy is different, but we hope that after reading this you don't feel alone. We want you to have hope that things can get better. Doctors can't fix everything but they can help a lot! We are here with you!

Your friends,
The kids crew!
Get to know your brain:

Your brain tells the rest of your body what to do. You can think of your brain making a phone call to parts of your body.

Just like you, your brain needs something to say on the call and a phone to make it. In your brain we call these parts "grey matter and white matter."

The gray matter comes up with what it wants to tell your body. The white matter is the telephone line that makes the message go super fast!
In leukodystrophy some of the white matter gets hurt. So your brain may have trouble sending the call. Think of a bad phone connection.

When this happens the message your brain is trying to send can be slow or have trouble going through at all.
Map of my brain?

Frontal Lobe (front-al)
make good decisions

Temporal Lobe (temp-o-ral)
Hear music and sound

Parietal lobe (par-ie-tal)
Feel what you touch
Walk, run and throw

Occipital Lobe (oc-cip-i-tal)
I see you!

Cerebellum (cer-e-bel-lum)
Balance
catch a ball yoga

Brain Stem
Heart rate, and breathing

Look at all of the cool things your brain helps you do!
What! Why do we have to talk about jeans?

Well there are a few types of jeans. We are not talking about the jeans you wear. We're talking about the genes that are in you.

Genes are like a cookbook. They tell your body how to make you. Your genes are part of your dna. They are what build the different parts of you.

Genes make you a boy or a girl and make your eyes blue, green, brown, or hazel.

Genes also make leukodystrophy.

When you have leukodystrophy there is a difference in one of your genes that can make part of your brain work a bit slower. You can't catch leukodystrophy. You are born with it.

Remember that there is nothing wrong with how you are made. Your genes also are part of what makes you so special. You are perfect just the way you are!
Some ways my Genes help make me, me:

Do you have dimples when you smile?
   Yes or No

Can you curl your tongue?
   Yes or No

I'm really good at:

Are you a Girl or Boy

My favorite part of my beautiful face

What is your eye color

How tall are you

Which hand you write with, right, left, both

What is you skin and hair color

A secret talent:
What does leukodystrophy feel like?

"Leukodystrophy doesn't hurt. My legs don't work and I can't walk because of it."

"It's sad to get sick. Don't worry the shots don't hurt"
Hi my name is Grady. I have ALD.

I was diagnosed last August. I had lots of appointments. Now I only have appointments every few days. I had to get a transplant so my ALD won't get worse. I got a transplant in September. I had to be at Children's Hospital almost a month. My transplant made me lose my hair and get weak. I worked out to make me stronger. The doctors tell me I can't play football but I can play basketball.

My hair is back now. I feel better, stronger and do basketball camp and won trophies.

Grady age 8
What's your story?
What is an EEG?
An EEG is done by putting lots of little stickers on your head. Each sticker has a wire that connects to a machine. These stickers and wires record all of the phone calls your brain is making. Here is what those calls look like on paper.

What is an MRI?
An MRI takes pictures of your brain. An MRI doesn't hurt at all but it is LOUD! When you have an MRI it is very important to stay still like a statue.
What to expect at your MRI

It's ok to be nervous before your MRI, but trust me, it will all be ok. You will get an IV before the MRI. The nurses are so nice and they will numb your arm so it won't hurt and you don't even have to watch. It's really quick.

Some kids will go to sleep for their MRI. Most older kids like me stay awake. It's hard to stay still and the machine bed is hard but the nurses and staff make you comfortable with pillows and warm blankets. Just try really hard not to move anything, especially your head.

I watch a movie with special glasses, like these. Sometimes I fall asleep on my own. Other kids listen to music.

The first MRI is the hardest but you can do it. It gets easier.
How to get ready for an MRI

Here are some tips for getting ready for your MRI:

- Practice laying still like a statue
- Pick out a comfortable outfit. Pajamas can be a good pick. Your clothes cannot have any zippers or snaps. NO METAL in the MRI. That’s because the MRI is made of a huge magnet!
- Pick out a movie or music you want to listen to
- Watch a video of an MRI online

How would you look as a statue?
Leukodystrophy can make parts of life hard. Some kids have trouble walking, or hearing, or talking with words. Some need help to eat or see. Luckily there are a lot of tools that can help! Do you know any of these tools? Are there other tools you use?
I don't want to go to sleep!

Why do I have to go to bed?
I don't want to go to sleep. Do you want to go to sleep?

Even if you don't want to go to sleep you have to. If you don't go to sleep you won't be able to do as many fun things as you get to do now!

What is so important about sleep anyway?

Well when you sleep your brain is giving you energy. And if you are not feeling good, sleep will help kill off the germs in you. Sleep also helps you learn.

WHAT? How can sleep help you learn?

Sleep helps you learn by having a practice of what you learned that day at night. Sleep also helps you grow! Sleep helps you grow because it isn't using food or energy up.
Night Routine

Having a good night routine is helpful for more than just having a bed time!

A good thing to start a night routine is to get all of the things together that you need for the next day. Like your lunch, snack, and all of the kind of stuff.

Some good tips for a night routine are:

- Stop watching TV 1 hour before bed.
- Having a story read to you is a good way to settle down.
- Go to bed earlier when you want to get up earlier.
- Another way is to have some sleep music.

Sleep and Seizures

If you have had a seizure before, sleep is extra important! Not sleeping can make you more likely to have another seizure.
Favorite Night Song

Something I sleep with

Picture of me sleeping

How sleep helps me
- Helps me grow
- Stay healthy
- Learn
Seizures

Have you ever had a seizure? Have you seen your brother or sister have a seizure? Seizures can look scary even to adults but guess what, seizures are not as scary as they look.

So what is a seizure? Remember that we learned that your brain tells your body what to do. It sends the message just like a phone call. Sometimes the brain gets confused and starts sending way too many phone calls all at once! When your body starts sending hundreds and thousands of calls we call it a seizure. Some kids shake when this happens. Some children stare into space. Luckily we have medicine that can help control seizures. Many kids feel very tired after a seizure!

"I don't usually know when I'm having a seizure. Sometimes Mommy says I am but I just feel 'not good'. I'd like other kids to know that the medicine is not good to taste but it helps me and it may help you too."

- Emily Age 8
If you see someone having a seizure, you should follow "Seizure First Aid". The Epilepsy Foundation has videos and even a class on seizure first aid that you can take.

Learn More:

**Seizure First Aid**
How to help someone having a seizure

**STAY** with the person until they are awake and alert after the seizure.
- Time the seizure
- Remain calm
- Check for medical ID

Keep the person **SAFE**.
- Move or guide away from harm

Turn the person onto their **SIDE** if they are not awake and aware.
- Keep airway clear
- Loosen tight clothes around neck
- Put something small and soft under the head

**Do NOT** restrain.

**Do NOT** put any objects in their mouth.

- Seizure lasts longer than 5 minutes
- Person does not return to their usual state
- Person is injured, pregnant, or sick
- Repeated seizures
- First time seizure
- Difficulty breathing
- Seizure occurs in water

Call 911 if...

Learn more: epilepsy.com/firstaid
My Pain Chart
Draw your own face chart

1. No Pain
2. A little pain
3. Some pain
4. Lots of pain
5. Worst pain

Things that help my pain:

Picture that makes me smile
What do you wish other kids knew about Leukodystrophy?

Have you had to do anything special to make school more fun or a little bit easier?

What do you wish your teacher knew about Leukodystrophy?
BOOKS WE RECOMMEND:

"I'm Gonna Like Me", Jamie Lee Curtis

Jack and the Pumpkin, Jean Bruce Cappelo

"The Great Katie Kate Explains Epilepsy", M. Maitland DeLand M.D.

"The Invisible Boy", Trudy Ludwig

"The Invisible String", Patrice Karst

"Today I Feel Silly and Other Moods That Make My Day", J. L. Curtis

"Your Fantastic Elastic Brain, Stretch It, Shape It", JoAnn Deak PhD