

National **Multiple Sclerosis** Society

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# KEEPS'MYELIN® ISSUE #20

## A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

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WHY DOESN'T MS JUST STAY THE SAME? We don't know We don't know exactly why, but we do know that a person with MS may have lots of energy at certain times of the day, but feel very tired at other times. We know that some people with MS have days or weeks or months when they feel better, and then days or weeks or months when they feel worse.

#### THIS CAN BE CONFUSING AND FRUSTRATING FOR EVERYONE!

Sometimes when a person is sick with a cold or fever, his or her MSsymptoms get worse for a while. When the cold goes away, the symptoms may get better. MS may feel worse when the weather is very hot and then feel better when the weather becomes cool and dry. And sometimes MS just changes! This is why we say MS is unpredictable.

#### UNPREDICTABLE MEANS WE DON'T ALWAYS KNOW WHAT TO EXPECT.

THE BEST WAY to deal with something that is unpredictable is by being prepared to change your plans if you have to. So, if your family has planned a day at the zoo, but then your mom or dad doesn't feel up to it, try to change your plans to something less strenuous. For example, you could decide to stay home and watch a movie together or have a picnic in the backyard. That's called being **FLEXIBLE**.

★ *T*'S AN IMPORTANT THING TO BE WHEN YOU HAVE MS IN YOUR HOUSE!



### MULTIPLE SCLEROSIS

(MS FOR SHORT) is a disease that affects the central nervous system (the brain, optic nerves and the spinal cord). The brain is like a computer that tells the body what to do. The spinal cord is like a thick wire attached to the computer. Messages travel between the brain, spinal cord, and other parts of the body.

INTERESTING FACT:

Multiple means MANY. Scierosis means SCARS.

WHEN A PERSON HAS MS the covering (myelin) that protects the nerves gets damaged. Scars form where the myelin is damaged. As messages travel from the brain, they sometimes get stuck or slowed down by these scars. When this happens, the other parts of the body can't always do what the brain is telling them to do.

**SOMETIMES** people with MS have trouble seeing. Sometimes their arms and legs feel weak or their skin feels "tingly" (like pins and needles). Sometimes they lose their balance, feel very tired, or have trouble walking. MS problems like these are called symptoms.

**SYMPTOMS** of MS can come and go. We don't know exactly why. Sometimes you don't even notice the symptoms. At other times they are pretty obvious. It's hard for a person with MS to know from one day to the next how he or she will feel. That is why we say that MS is unpredictable.



#### KEEPSMYELReaders WE WANT YOU We love to publish your pictures, stories, and poems about MS. PLEASE SEND US YOUR WORK:

So, multiple MANY Scletosis means

Tell us how your family learns about MS together, how you feel about having MS in your family, what advice you would give other kids about having a mom or dad with MS, how you help your mom or dad, or whom you talk with about MS.



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900 South Broadway, Suite 200 Denver, CO 80209 or e-mail to: KEEPSMYELIN@NMSS.ORG My dad says that going to the beach isn't fun for him anymore. When he gets hot, his MS feels a lot worse. He has trouble walking and his vision gets blurry. Why does that happen? How can I help him feel better?

'E ANSWERED.

ED,

Many people with MS feel worse when their body gets **OVERHEATED**. When the body's temperature goes up—even a tiny bit—the messages that travel from the brain to the rest of the body can't travel as fast. This makes a person's symptoms act up until his or her body cools down again. Hot weather, exercise, or a fever can all cause someone to feel uncomfortable for awhile. This is called a pseudoexacerbation (soo-doe-egg-zass-er-bay-shun) — try saying that three times fast!). The good thing is that people begin to feel better as

soon as their body temperature returns to normal. You can help your dad by helping him stay cool. He should stay out of the bright sun, drink lots of cold drinks, and maybe even wear a cooling collar or vest to help his body STAY GOOD.

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MOMMYHASMS by: Madison (7 years old)

My mommy has MS and I don't like it. I wish that they can find a cure because I want my mommy to be happy and play with me.

I hope and hope they find a cure for my mommy.

My mommy takes shots all the time, but she still lets me sit in her lap.

a N Madison

by Bobbi Sue (age 12)

My dad has MS. He lives just fine. Sometimes it gets rough to survive. But hey, he's still around. He might worry me from time to time. I wonder what to do. Mom's always there to calm me down.

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He loves us both very much. And we love him very much back.



I talk to my best friends and they understand they help me out a lot from time to time. They are very trustful.

> MS, I wish would leave for good and never return to my Upside down world.

#### Ben:

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"Gee, it's really hot today. I hope my mom is OK. I've heard that heat can make MS worse for a while."

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#### Michael:

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"Maybe your mom could wear a 'cooling vest.' It's a neat vest with lots of pockets that hold those frozen ice packs—the kind that keep your lunch cool. It keeps your whole body cool!"

#### Crystal:

Hey Ben, you should tell her about it.... And get one for me too!!!

1. The covering around the nerves
is called 2. The physical problems caused by MS are called
<ul> <li>3. MS can change from one day to the next - that's why we say it's</li></ul>
<ul> <li>5. Many of the messages going from the brain to other parts</li> <li>of the body travel along the</li></ul>
7. The words multiple sclerosis mean
PICK OUT YOUR ANSWEIGER * PICK OUT YOUR ANSWEIGER Computer Symptoms Computer Computer
Myelin Nelin Myelin
Suptomer & Unpredictable, 4. Central nervous system, 5. Spinal Cord     Suptomer S. Unpredictable, 4. Central nervous system, 5. Spinal Cord     Suptomer S. Unpredictable, 4. Central nervous system, 5. Spinal Cord     Suptomer S. Unpredictable, 4. Central nervous system, 5. Spinal Cord     Suptomer S. Unpredictable, 4. Central nervous system, 5. Spinal Cord     Suptomer S. Supervise S. Supe

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Hint: words are across, down and backwards!

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COLD HOT AUTUMN SUMMER ICE HUMIDITY LEAVES BREEZE SUN SPRING RAIN WINTER



National Multiple Sclerosis Society

900 S. Broadway, Suite 200 Denver, CO 80209



# Families can count on the National MS Society!

To learn more about the resources available to you and your family, please contact an MS Navigator at:

### 1-800-344-4867

which is faster: heat or cold?

Heat, because you can catch cold! ANSWER:

David's father has three sons: Snap, Crackle and —?

PINED : BANNA

What kind of car does Mickey Mouse's wife drive?

> **SAWSWA:** A Minnie V<sub>an</sub>!