



# KEEP SMYELIN'

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

## MS CHANGES

**MS** often changes. It may change over the course of a day, over the course of a week or month, and maybe over the course of a year. Why doesn't MS just stay the same? 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!

**S**ometimes when a person is sick with a cold or fever, his or her MS symptoms 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.

**T**he 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 back yard. That's called being flexible. It's an important thing to be when you have MS in your house!



# MS

**Multiple sclerosis** (MS for short) is a disease that affects the central nervous system (the brain 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 from the brain, along the spinal cord, to the other parts of the body.

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, or sometimes it's

hard to walk. 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.

**Interesting Fact:**  
*Multiple means many. Sclerosis means scars. So, multiple sclerosis means "many scars."*

We love to publish your pictures, stories, poems, and interviews about MS. Please send us your work! 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, and whom you talk with about MS.

**Send your stories and pictures to:**  
**KEEP S'MYELIN, National MS Society**  
700 Broadway, Suite 810,  
Denver, CO 80203 or e-mail them to  
[keepsmyelin@nmss.org](mailto:keepsmyelin@nmss.org).



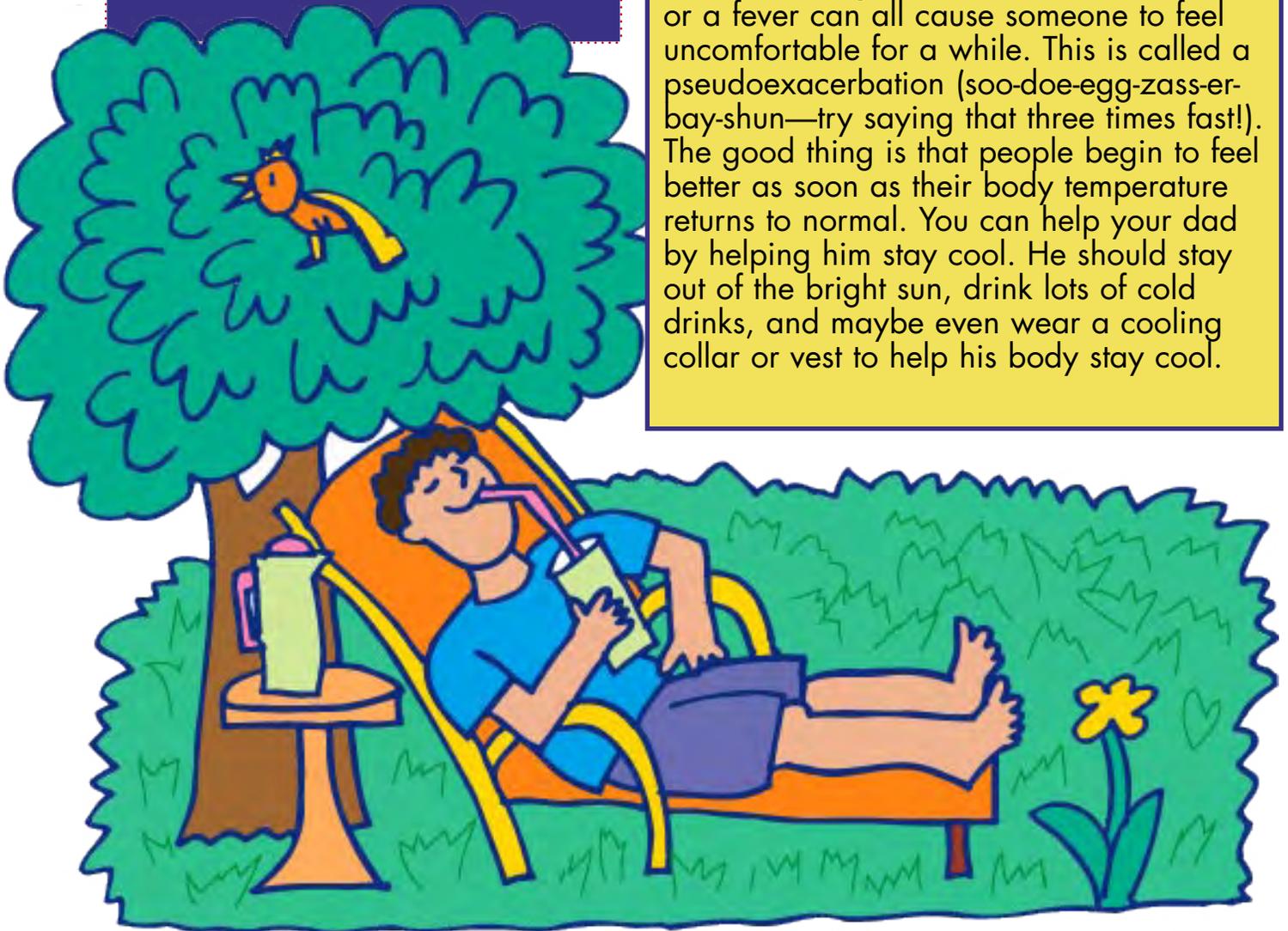
# ASK the DOCTOR

Q

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 bet-

A

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 a while. 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 cool.



# MS in My Life

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. He loves  
us both very much.  
And we love him very  
much back. I talk to my best  
friends and they understand  
and so 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

# My Mommy Has MS

by Madison, age 7

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!

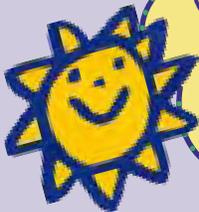
Madison



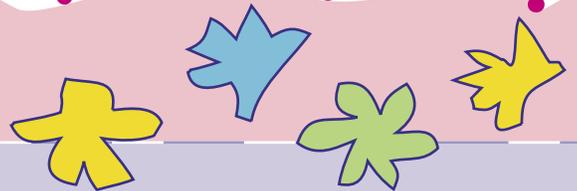
# MY MOM AND MS

by Mattias, age 8

(Mattias was a team captain at the MS Walk. She and friends from church raised \$1,700 for MS!)



My mother cannot run  
I think that is not fun  
She loves me a ton  
Because I'm her only one  
Sometimes I hate MS  
It causes a big mess  
She should not go in the heat  
For it makes her really feel beat  
Dad and I want a cure  
She is brave, that's for sure.



## JOKES

Q: Which is faster:  
heat or cold?

A: Heat, because  
you can catch cold!

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

A: A Minnie van!



Q: David's father  
has three sons  
: Snap, Crackle  
and \_\_\_\_ ?

A: David





# SEASONS WORD SEARCH

L	E	A	V	E	S	S	N	H	B	H
Q	A	U	A	B	U	K	N	E	O	L
V	S	T	L	E	M	B	W	O	A	T
B	T	U	E	A	M	R	E	I	W	Y
G	E	M	N	C	E	E	A	C	H	T
T	R	N	T	H	R	E	R	E	Z	F
S	P	R	I	N	G	Z	T	X	M	O
R	B	H	N	Y	D	E	R	A	I	N
T	P	R	E	S	I	D	E	N	T	S
N	E	W	Y	E	A	R	R	N	T	S
K	W	A	N	Z	A	L	A	B	O	R

LEAVES

SUMMER

BEACH

VALENTINE

PRESIDENTS

AUTUMN

ICE

SNOW

BREEZE

LABOR

HOT

SPRING

KWANZA

RAIN

NEW YEAR

EASTER

MICHAEL  
CRYSTAL

AND  
BENJAMIN

# S'MYELIN KIDS

IT'S REALLY HOT TODAY. I HOPE MY MOM IS OK. I'VE HEARD THAT HEAT CAN MAKE MS WORSE FOR A WHILE.

MAYBE YOUR MOM COULD WEAR A COOLING VEST. IT'S A NEAT VEST WITH LOTS OF POCKETS THAT HOLD FROZEN ICE PACKS—THE KIND THAT KEEP YOUR LUNCH COOL. IT KEEPS YOUR WHOLE BODY COOL!

HEY BEN, YOU SHOULD TELL HER ABOUT IT... AND GET ONE FOR ME TOO!

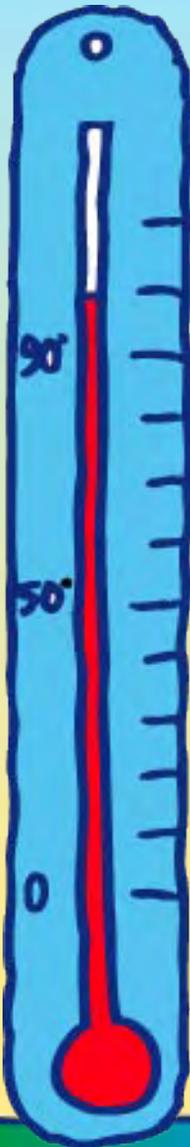


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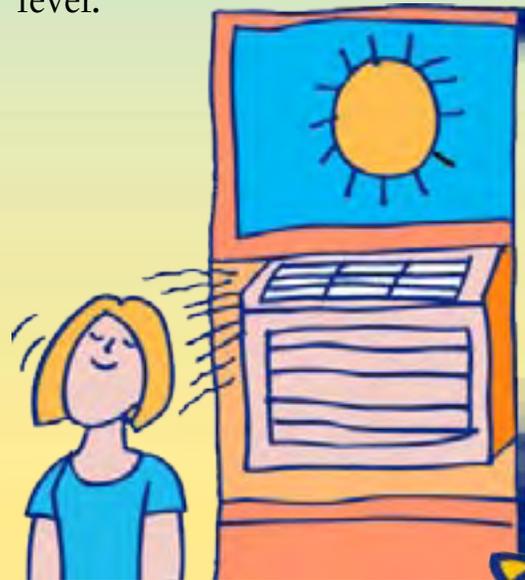
## PARENTS' PULL OUT

### How to Read this Issue with Your Child

One of the biggest challenges for parents with MS is how to help their children understand its variability and unpredictability. In many ways, children tend to be quite logical; they rely on what they see to draw conclusions about what's going on. As a result, they find it hard to understand why mom or dad can look pretty much the same from one hour to the next, or one week to the next, but feel so different. Because so many of the symptoms of MS aren't visible to them, they can easily become confused about why their parent has the energy to play with them one day but not another. This issue of Keep S'myelin will give you the opportunity to talk about several reasons why your MS may feel different at different times.



Most people with MS are temperature-sensitive—most to the heat and humidity, but some to the cold. You can talk with your child about the ways you try to manage the longer temperature changes that come with the seasons or the more temporary changes that come with exercise or a fever.



*(Continued on page 2)*

(Continued from page 1)

Although children are pretty logical, they also have excellent imaginations. As you describe how your body feels with the temperature changes, ask your child to imagine or draw a picture of what you're feeling—e.g., pins and needle sensations, blurry vision, heavy arms or legs. Making a cooling scarf will give your child a chance to feel like an important helper.

The unpredictability of MS can make planning very difficult. As you read this issue, take the opportunity to talk about the importance of having back-up plans for family activities. When planning an outing, a party, or a vacation, take time to talk about what you would do if the MS got in the way. Children have an easier time dealing with cancellations, changes or postponements if the back-up plan is clearly understood by everyone. And as Madison reminds us, climbing into mom's lap is always special, even if some other activities aren't possible.



As you read Bobbi Sue's poem together, let your child know that it is OK to share feelings and worries with you, the other parent, a best friend, or a favorite aunt or uncle. Sometimes children worry that their parent with MS would be upset if they shared their feelings with other people. They need to know that getting support from others is an important way of dealing with the unpredictability of MS.





# COOL FRUIT SMOOTHIE



(Drinking something cool on a hot day can actually lower your core body temperature—and make you feel better!)



- 1 banana — peeled
- 1 cup strawberries — hulled and sliced
- 1 cup orange juice
- 1 tablespoon honey
- 1 cup ice — crushed

Add fruit, juice and honey in a blender. Blend on low speed to mix. Stir in ice. Blend on high until smooth. Makes 3 8-ounce servings.



KEEP S'MYELIN is available on line at [www.nationalmssociety.org](http://www.nationalmssociety.org)  
You can e-mail us at: [keepsmyelin@nmss.org](mailto:keepsmyelin@nmss.org)

PARENTS' PULL OUT

# HOT WEATHER TIP

1. Take a bandana and soak it in water. Place the bandana in the freezer. Let sit until frozen.



3. Wrap the bandana around your wrist or neck.



2. Take out and thaw until it is bendable.



How can you subscribe to Keep S'myelin?

Call 1-800-FIGHT-MS  
1-800-344-4867



You will be connected to your chapter. Ask them to add your name to the Keep S'myelin distribution list. **IT'S FREE!** Keep S'myelin is published quarterly by the National MS Society. **Past issues** are also available at your chapter.

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Keep  
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MS ACROSS  
THE YEAR

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**Keep S'myelin** is a quarterly publication for children with parents or other relatives with multiple sclerosis. It is produced by the **National Multiple Sclerosis Society**. The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent therapeutic recommendations or prescriptions. For specific information and advice, consult a qualified physician.

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*The mission of the  
National Multiple  
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end the devastating effects  
of multiple sclerosis.*