

#### A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

#### I have a teacher with MS

by Emily G.

My teacher, Ann B., is full of life. She teaches with tons of energy

and excitement, which is why the entire class was very surprised when she told us she has MS.
She explained that

sometimes her body is a little tired and not very strong, but that she is still the same person she always has been. She can still teach us and we don't need to worry. MS is not contagious,

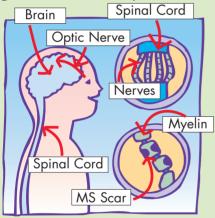
and we are not scared that we will catch it.

Last year many students from my class joined Ms. B on the MS Walk to help raise money to find a cure for MS. This was an exciting event and everyone was happy to support such a wonderful cause. To learn more about Ms. B please read her story on page 4.

We are comfortable being with her and my class has fun helping her. During class we help her with little things like opening windows, organizing the room or carrying text books. We sometimes get to write the daily notes on the board. We enjoy being able to do things for our teacher.

## MS

Multiple sclerosis (MS for short) is a disease that affects the central nervous system (the brain, optic nerve 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."

#### Keep S'myelin Readers: WE WANT YOU!

We love to publish your pictures, stories, and poems 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, or whom you talk with about MS.



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Denver CO 80209
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Send to:



# YOUASKED?



What causes MS?

Even though we have known about MS for more than 100 years, scientists still don't know what makes people get it. They have studied lots of "bad guys" like viruses and studied lots of "bad guys" lik

Who was the first person to get MS?

Why did my mom get MS?



Since doctors and scientists still don't know what causes MS, they aren't sure why one person gets MS and another person doesn't. It just happens sometimes. But your mom didn't do anything that caused her to get MS and we don't know of anything she could have done to stop it from happening—so it's not her fault or anyone else's fault either.

No one can be absolutely sure who got MS first. Doctors think that a young woman named Sister Ludwina van Schiedam was one of the earliest. She fell down one day in 1396–700 years ago—and the doctors' descriptions of her problems with walking and balance to sound a lot like MS. But MS didn't get its name for another 472 years!

#### I Am a Teacher

#### with MS

My name is Ann B. and I am a teacher who has MS. That does not mean that I can't do "stuff." I just had to learn to do things in a different way. Does your mom or dad get tired sometimes? Well, that happens to me, too. So now I plan my day to make sure I have the energy to do what is important for my students and me. When your mom or dad gets tired, you should plan on that being the perfect time to read a book or watch tv toaether!





Sometimes my legs don't do exactly what I want them to. I used to be able to walk all over the classroom. Now when I need to I teach sitting down, and I need to sit on my stool most of the time.

Sometimes I forget a word right in the middle of class! I've learned to say to my students, "I am thinking of a word..." and they help me out. They think it's a game and they love it. If your mom or dad has trouble remembering maybe you can help too.

The important thing to remember is that when MS makes your mom or dad weak or tired or forgetful, they are still your mom and dad! I have good days and bad days, and guess your mom or dad do too. I always tell my students that I will always try my best. With their help I can make it through anything!



### Is your school accessible?

Do you know what <u>accessible</u> means? A place is <u>accessible</u> if everyone can come and go and move around easily. Even someone who uses a wheel-chair or crutches or can't see very well will not have any trouble getting around if a place is <u>accessible</u>.

A school is accessible when there are no stairs to climb (or a ramp is available) so a wheelchair-user can get to the front door. It is accessible when the doorways are wide enough to let a wheelchair through. It is accessible when a person in a wheelchair can get to every room in the school, upstairs and down. It is accessible when there are roomy bathrooms. It is accessible when there are signs with very big letters that tell the classroom numbers.

You can look to find out if your school is accessible by using this checklist. Walk around your school with an adult friend who can help you answer the questions below. This can help you figure out, for example, if a parent using a wheelchair can come to Open School Night, or a student using crutches can get around easily in your school.

- 1. If there are stairs leading to the front door of your school, is there a ramp, too?
- 2. Is the ramp at least 36 inches (3 feet) wide? Are there railings on both sides of the ramp?
- **3.** Are the doorways in your school 32 inches wide (or more?)
- **4.** Can someone with weak arms open the doors easily?
- **5.** If there are stairs inside your school, are there also elevators or ramps that a person in a wheelchair can use?

- **6.** Is the bathroom roomy (at least 5 feet across?)
- 7. Are there grab bars in the bathroom next to the toilet? Are they about 33 inches high?
- 8. Are there signs on the bathroom doors that say BOYS and GIRLS in big letters (so they are easy to see?) Are the signs in raised letters or Braille, too?
- 9. If there are carpets in your school, is the carpet low pile (less than one inch high?) It's hard to roll a wheelchair over a thick pile carpet.



## A-MAZ-ING FUN!

Help the kids find their way to school.



ENTER



## My mom has MS

by Meris

My name is Meris and I am 11 years old. My mom has had MS since I was 6 months old. I help mom in many ways, but the great one I do is I my mom in many ways, but the great one I do is I try my best to cheer her up. She says she is happy as long as try my best to cheer her up. She says she is happy as long as she has me. I also have a sister and her name is Ashleigh. She is also a great helper.



JOKES

Where was the Queen of England crowned?

On her head.

How do you know if a hippo is sitting next to you in school?

There's an "H" on his pencil case.

Where was the Magna Carta signed?

At the bottom.

How do mushrooms count?

With their fungus.

Where are the Andies?

.esimne nuoy to bns sht tA

What do you call a vampire adding numbers?

Counter Dracula.

### We want to hear from you!

Please send us your stories, poems and pictures to:

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900 South Broadway
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or keepsmyelin@nmss.org



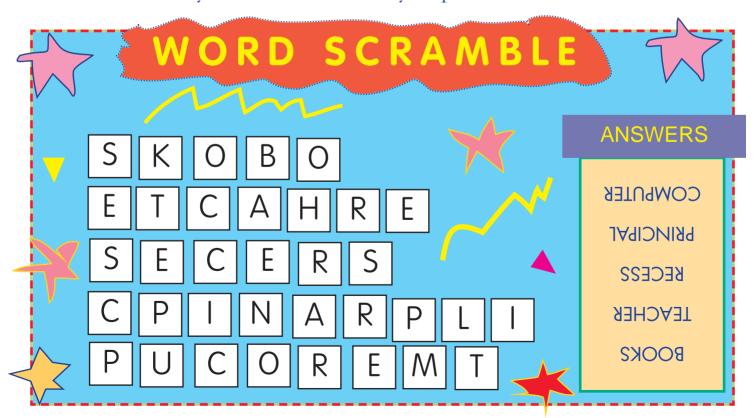








Contact your National MS Society chapter at 1-800-344-4867.





National Multiple Sclerosis Society

ISSUE #4 SCHOOLS

Research

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#### PARENTS' PULL OUT

#### How to Enjoy Keep S'myelin with your kids

School is the backdrop for a very significant part of your child's life. Family and home issues are brought to the school environment just as school experiences influence home life. Use this issue of Keep S'myelin to help you talk with your child about his or her school experiences, especially as they relate to MS in the family.

Read "Is Your School Accessible" together to talk about whether the school is welcoming and barrier-free for people with disabilities.

Arrange to conduct an accessibility survey of the school with your child using the questions provided.



— Use the material in "I Am a Teacher with MS" to help your child think about what adaptations this teacher has made to continue doing her job. This is an opportunity to raise awareness about the ability of people with disabilities to make accommodations and contribute to society in many ways.

— Encourage your child to submit materials for future issues of Keep S'myelin!



— Stay involved with your child's teacher and school. Attend school events, volunteer at school, and participate in parent-teacher conferences!



#### PARENTS' PULL OUT

## Making the Most Out of Parent-Teacher Conferences

Parent-teacher conferences are the most common means of communication between parents and teachers. Use these meetings to build a relationship between home and school. Here's how you can prepare and make the most out of the experience.

— Call the school in advance if you need any accommodation or are concerned about accessibility.

— Discuss the conference with your child in advance to determine whether he or she has concerns about school that you should discuss with the teacher.

For example: Are there special friends they like to work or play with at school? Are they concerned about children who tend to tease or bully? Are there subjects that are especially difficult for

your child? What are their favorite

favorite activities at school?

— Write your questions for the teacher in advance and bring your list with you.

— Take notes so you will remember what's been discussed.

— Ask to see examples of your child's work.

Ask the teacher what you can do to participate in your child's education.

— Ask the teacher the best way to communicate between conferences (e-mail, notes, telephone).



#### PARENTS' PULL OUT

## Helping your child deal with TFASTNG

(excerpted from "Easing the Teasing: Helping Your Child Cope with Name-Calling, Ridicule, and Verbal Bullying" by Judy S. Freedman, 2002 (http://www.eric.ed.gov Education Resources Information Center.)

Parents can't always protect their children from hurtful teasing at school, but they can teach their children ways to deal with it. Not all teasing is harmful; it can be fun and constructive when it is good-natured and playful and causes everyone to smile. Hostile teasing, however, can feel tormenting to a child and may require intervention.

#### STRATEGIES FOR PARENTS

— Don't overreact. Your overreaction can escalate your child's reaction.



— Convey the message: "You can handle this."



- Encourage your children to play with kids with whom they feel comfortable.

— Do you model good behavior? Do you tease your children inappro priately? Do you model 'victim' behavior?

#### TEACH THE STRATEGIES BELOW.

#### STRATEGIES FOR CHILDREN

- Self-talk: Help your children think about what they might say to themselves when they are being teased ("I can handle this..." "What they're saying isn't true...")
- Ignore: Help your child understand that tears or anger may just encourage the teaser. The child should try to pretend the teaser is invisible or walk away if possible.

(Continued on page 4)

#### PARENTS' PULL OUT

#### (Continued from page 3)

— Visualize: Help your child visualize the words bouncing off them or visualize a magic shield that protects them from hurtful words.

— So?: The response of "So" may convey the indifference the teaser needs to take the wind out of his or her sails.

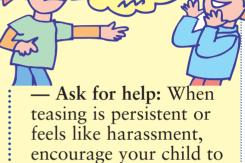
— Agree with the facts: The teaser says: "You have so many freckles!" The child responds with "That's right, I do have

lots of freckles!"

The teaser taunts:

"Your mom
can't even
walk."
The child
responds
"You're
right, she
uses a scooter
to get round."

— Use humor: Laughing or humor can turn a hurtful situation into a funny one.



get an adult involved to

KER S'MYEKIN

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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 Sclerosis Society is to end the devastating effects of multiple sclerosis.

#### Please give us feedback.

Send your questions or ideas to:

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