



Keep S'myelin

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS



My mom has MS



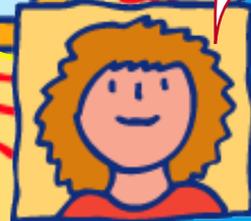
I went to the MS Walk



My grandfather had MS



My grandma had MS



It's time again to share with you some of the wonderful stories and poems that readers have sent to Keep S'myelin. In these poems and stories, kids share their thoughts about having MS in the family. Even though having MS in your family can be sad and sometimes hard, there are still lots of good, hopeful, and fun times in every family.

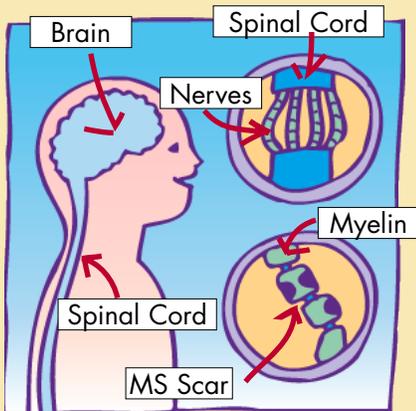
Use what you know about MS to play the "What Would You Do?" game. Enjoy finding the silly mistakes in "What's Wrong with this Picture?"

And remember to always Keep S'myelin!

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."

Keep S'myelin Readers:
WE WANT YOU!

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.



INTERVIEW WITH

JESSICA



Jessica is 9 years old and in the 4th grade in Eldon, Missouri. Her mom has had MS for about one year. Jessica has a brother, Tyler, who is in the first grade, and a dog named JO.

KS: How did you learn that your mom had MS?

JESSICA: She told me when she came home from the doctor. She had an IV* in her arm and I didn't know what it was. I didn't know anything about MS until then.



* An IV is a little tube that the doctor can place into your arm to bring medicine to your body.

KS: How did you feel when you first learned she had MS?

JESSICA: I was nervous and scared. I wondered, would it go away? Would my mom always be tired and numb?

KS: Whom did you talk to about it?

JESSICA: My mom, and I told my friends. Also my grandparents and my teacher. They all understood and it helped to talk to them.

KS: How did you learn about MS?

JESSICA: From Keep S'myelin. My mom and I read it together and I read some of it on my own, and then I asked my mom questions. I also like the puzzles and jokes in Keep S'myelin!

KS: What advice would you give another kid who just found out her mom has MS?

JESSICA: Ask questions if you want to know what MS is about. Don't be scared—your mom won't die. Help out at home.

KS: How do you help?

JESSICA: I give my brother a bath and I dust and help with the laundry. And when my mom is resting, I leave her alone!

KS: What has changed in your house since MS?

JESSICA: We don't stay up as late, because my mom is tired. But she is feeling much better now than when she first found out she had it.

Reader-Submi

1

My Mom Has MS

My mom has MS. I have a big sister. Her name is Jenna. She is 13. Me and my sister help my mom a lot and a lot and a lot! I wish I knew another kid's mom with MS, but I don't. It is hard having a mom with MS. Maybe if we find out why she has MS, they can take it away.

Claire, Anchorage, AK

2

Tori's Story

My name is Tori and I am 14 and in the 9th grade in Detroit, Michigan. My mom is in remission with MS. When I was little, my mom's knee would always give out and she fell down stairs all the time. I never really understood. She took me to the doctor's with her to get an MRI and she had two scars on her brain. She finally told me she had MS when I was 10. I was so scared!

Last year, we went to the 2004 MS WALK in Michigan. I loved walking for something that will help find a cure for MS! My mom has to go get an MRI to see if she has MS problems again or not. I am scared, but one thing will not change—she'll always be my best friend!

Tori, Eastpointe, MI

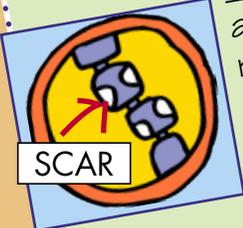
MS Words in Tori's Story

REMISSION: A period of time when MS seems to go away or get better

MRI: A special test that shows pictures of the brain and spinal cord

SCARS: Places in the brain and spinal cord where myelin is damaged. On an MRI (see left), the scars look like white dots.

MS WALK: A National MS Society event where people walk together to raise money for research and services.



tted Stories

My Grandma

3

My name is Andriana. I am 8 years old and in the 3rd grade. My grandma had MS for 34 years. I was her legs forever! Me and my grandma would help each other. She helped me with my homework. My grandma used a wheelchair. She was always happy when I came over. I made her bed. I took good care of her. After school I would go to her house. I would be with her when she was alone. When I helped my grandma, she was happy. My grandma died in a hospital. I miss my grandma. She was a great grandma. And that is my story.

Andriana, Spring Creek, NV

Tyler Helps Out

4

My name is Tyler and I am 11 years old. My grandfather had MS. When I was 3 years old, my mom (his daughter) was diagnosed with the same disease.

I'd like to share with other kids how I help my mom. I do a lot of things around the house to help out and I always have. But the biggest thing I do for her (and in memory of my grandfather) is the MS WALK. Last year, I was a top fundraiser in Washington State. I raised over \$2,000 last year and again this year. This spring, my mom and I flew from our new home in Maryland back to Washington to be honored for our efforts. I gave a speech about my grandfather and introduced the MS Honoree, my mom! My mom has a WALK team called Team Hope. They are famous in Washington. They raise over \$10,000 each year at the WALK. I'm proud to help my mom and researchers around the world because I know that one day soon, there will be a cure.



Color in this Picture:
 Can you find all the silly things
 in this picture?



Jokes

What dog loves
 to take bubble
 baths?

A shampooe!



What did the jack say
 to the car?

"Can I give you a lift?"



TEACHER: Why does the
 Statue of Liberty stand
 in the New York harbor?

PUPIL: Because it
 can't sit down!



What Would You Do?

Talk to your mom and dad about what you would do.

PARENTS:
See suggested answers in the Parents' section



This girl and her mom want to get into the library, but there are too many stairs. **What would you do?**



This girl just found out that her dad has MS. **What would you do?**



It's very hot out and this dad with MS has been out in the yard for a very long time. **What would you do?**



PARENTS' PULL OUT



HOW MUCH IS TOO MUCH?

With so much emphasis on the importance of sharing information about MS with your children, you may find yourself wondering, “What is enough? What is too much? Are we giving MS more time and attention than it should have?” Obviously there is no single answer that is right for every family, but here are some thoughts to keep in mind:

- It’s important to give MS as much space as it needs in your family, but no more than it deserves. That means that you need to acknowledge its presence and the ways that it impacts family members and family activities, but there is no need to make it the center of family life or

the focus of every conversation.

- Although all children have questions and concerns about MS and its effect on their mom or dad, they are not thinking or worrying about it all of the time. In fact, it may sometimes seem as though they don’t think about it at all. The best strategy is usually to explain what is going on before they have to guess (e.g., if you are having a bad day, taking an injectable medication, using a new mobility aid, going into the hospital for treatment), and be available to answer questions or deal with feelings as they arise.

- Everything isn’t about MS—kids can have their bad days just like we do. Don’t jump to the conclusion that their moods or worries are all about you.

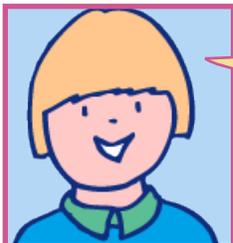
- Children of different ages need different amounts and kinds of information, and each child has his or her own preferred style of learning. One may want to read Keep S’myelin or look up information online while another loves going to a chapter-sponsored family program. One may ask you a lot of questions while another may ask the other parent or nobody at all. You will need to tailor your conversations to the needs of each child; one size doesn’t fit all.

PARENTS' PULL OUT

- A good strategy for preventing MS from having too big a place in your household is to give family members the opportunity from time to time to share their feelings about it. When feelings get bottled up, with no place to go, they begin to wear people down. It's like that big elephant in the middle of the room that no one mentions but everyone trips over as they try to go past. Just as you have feelings about the ways MS has changed your life, kids have feelings when they have extra chores or when outings have to be cancelled because of MS. Being able to share those disappointments and frustrations with one another helps clear the air so everyone can get on with their lives.

- Some families may feel that every aspect of their lives has been altered by MS. Sometimes it helps to have an "MS-free" time, where the focus is on family fun or just the day-to-day business of being a family. This "MS-free" time provides an emotional respite from the day-to-day challenges and losses and re-focuses attention on just being a family.

- Living with MS requires some creative problem-solving. When family members problem-solve together, everyone benefits. Adaptations are made, challenges are met, and chores get done—leaving more time for family fun.



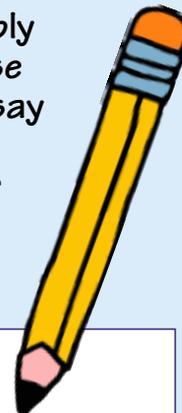
KEEP S'MYELIN is available on line at

www.nationalmssociety.org

You can e-mail us at: keepsmylelin@nmss.org

What Would You Do?

This game, on the activity page 7 is a good way for children to apply what they know about MS to solve some problems. Do this exercise with your children. Have them think about what they would do or say if they observed the situations described. Here are some possible responses. Help your child talk through the consequences of their responses, thinking about what would be most helpful and why.



POSSIBLE RESPONSES:

- Turn around and go home
- Get someone to help lift the wheelchair wheels over the curb
- Find an accessible entrance around the side or back of the building
- Call the mayor and let him/her know about accessible buildings



POSSIBLE RESPONSES:

- Bring him a cold drink
- Remind him that heat can sometimes make MS worse temporarily
- Suggest that he put a cold washcloth on his head



POSSIBLE RESPONSES:

- Give her a hug
- Tell her about the National MS Society and Keep S'myelin
- Tell her she's not alone
- Reassure her that her mom and dad will always love her and take care of her

PARENTS' PULL OUT

RESOURCES

FOR FAMILIES



MS Journey Club

MS Journey Club is a multi-session in-person educational/social program for parents with MS and their children ages 5-12. The program covers a wide range of topics including feelings, communication, support systems, and how to have fun. If you are interested in participating in MS Journey Club, please contact your chapter at:

1-800 FIGHT MS.

Timmy's Journey to Understanding MS

Timmy's Journey to Understanding MS is a 15-minute animated cartoon that follows a young boy named Timmy as he learns about MS from his guide, Captain Kip S'myelin (voice of David Lander). Captain S'myelin takes Timmy through the world of MS – symptoms, treatments, and feelings. The cartoon is an excellent tool to help parents talk with their children about MS. Copies of the cartoon may be available through your chapter's lending library, or can be purchased by contacting your chapter.



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
S'myelin
**KIDS TALK
ABOUT MS**

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



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.*