



KEEP SMYELIN

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

WHY NO CURE YET?

Grownups are always saying, "Be patient!" But it's hard to be patient waiting for the cure for MS. Do you ever wonder why it is taking so long? There are lots of reasons. For one, scientists can't figure out a cure without knowing what causes MS. There are lots of clues, and these are like pieces of a gigantic jigsaw puzzle that scientists all over the world are trying to put together.

There are so many puzzle pieces! MS attacks a very complicated part of the body – the central nervous system (the brain

and the spinal cord)—and scientists need special tools to figure out what's going on in there. Another complicated part of the body that is involved in MS is the **immune system**. This system is made to help our bodies fight germs, but something goes wrong in MS and the immune system attacks the central

nervous system instead! Scientists are looking for the puzzle piece that would will give them the power to turn

off the attack forever.

The good news is that scientists are making lots of progress filling in pieces of the puzzle. And, they're also learning a lot from research being done in other diseases. So, we hope soon that all of the pieces will come together and the answer will be in front of us. Then we won't have to be patient anymore, because we'll have a cure!

See "What is MS" on page 2 for more information.

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."

What would a cure for MS look like?

Maybe, it will be a vaccine to keep people from ever getting MS. This would be like the shot you get from your doctor so you won't ever get the measles or mumps. Or, maybe it will be a medicine that makes MS go away once a person has it. Or, maybe it will be a cure that helps the cells in the immune system do what they are supposed to do—like fighting germs—rather than damaging the myelin and nerves the way they do in a person who has MS. Scientists are exploring all these possibilities, and more. And maybe,

the cure will turn out to be something that no one has even thought about yet. What do you think it will be?



ACCEPTANCE SPEECH FOR FINDING A CURE FOR MS

Here is a "speech" that Sid wrote for his creative writing class at the Doris Eaton School in Walnut Creek, California. In this speech, Sid imagines that he has found a cure for MS! Do you dream about finding the cure for MS? Tell us your dreams.

I am honored to have won this award for finding a cure for multiple sclerosis. It all started when I heard about MS from a doctor at a school assembly. I was very bothered by how awful the disease is and its effect on human lives. So, I decided to find a cure for MS no matter how long it took.

I researched websites, talked to experts, and learned as much as I could about possible cures for this disease. I traveled through every continent, ocean, and sea, but nothing cured my patients. So, I went to space searching. On Mars, I found a glowing herb. I brought the herb back to Earth and tested it on a patient. He recovered fully and became very healthy. I felt so good that the patient was cured and no longer had any problems.

I am now in a program that grows the special herbs and produces the medicine called Cure-a-Bunch. I will continue my research and hope that we make medical breakthroughs and find cures for all diseases.

Thank you very much.

You can send us your stories by e-mail at keepsmyelin@nmss.org or send them to: Kim Koch, NMSS, 700 Broadway, Suite 810 Denver, CO 80203.



A POEM

BY GRACIE, 9 YEARS OLD

MS you are a pest! You're worse than all the rest.
It would be best, MS, if you leave my mom alone!

I love my mom, very much, she has a motherly touch.
It's really sad and very bad that she had to have MS!

MS you are a pest! You're worse than all the rest.
It would be best, MS, if you leave my mom alone!

JOKES

What part of a ship is made out of cards?

The deck.



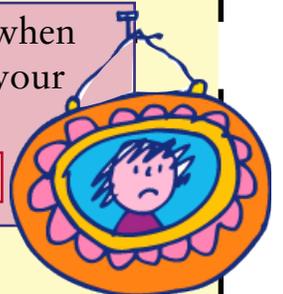
What is the difference between here and there?

The letter I.



What happens when you don't dust your mirror?

You get a dirty look.



Why did Joe keep his trumpet in the fridge?

Because he liked cool music.



Dr. CLAUDIA
LUCCHINETTI:
MS
Detective



We spoke with Dr. Claudia Lucchinetti, a doctor at the Mayo Clinic in Rochester, Minnesota. She has two children, ages two and five.



KS: What kind of doctor are you?

Dr Claudia: I am a neurologist and a research scientist.

KS: How do you spend your time at work?

Dr Claudia: I spend about half of my time taking care of patients with MS, and the other half in a laboratory studying MS.

KS: How many years did you go to school to be able to do the work that you do?

Dr Claudia: I went to elementary school, high school, college, and medical school, which equaled 20 years, and then I had five more years of special training to be a neurologist and MS researcher.

KS: How did you get interested in MS?

Dr Claudia: When I was 18 years old, I worked in a laboratory with another doctor who was taking care of people with MS and doing research, and that got me started.

KS: If we think of finding the cure for MS as a big puzzle, how would you describe the piece that you are working on?

Dr Claudia: We know that MS causes small scars in the brain and spinal cord. I look at these scars through a microscope to find out what might have caused them and what is happening inside them. Different people seem to have different types of scars, and we are trying to figure out what causes the differences, and whether different medicines might be used to treat different kinds of scars.



T'Keyah's

S T O R Y

Hi. My name is T'Keyah. I am ten years old and my mom, Tyanna, got MS last year. When my mom first got MS, my dad, John, had to take my mom to the hospital because she was very sick and could hardly walk and my five-year-old brother Ja'Waun and I were very scared. But after my mom came home a few months later, she was back to her old self, except that she had a little leg weakness sometimes.

When it started, we thought mom would have to be in bed all the time or in a wheelchair and although we don't know what the future will bring, we love how positive my mom stays because of her faith in God. My mom learned about the MS Society and started getting books from them and Keep Smylein for us so we could better understand MS. My family and I will never give up on her and will take better care of her and try not to stress her out. And, I even learned how to do the laundry to help my mom out. And I pray every night they find a cure for MS.



That's me T'Keyah holding the sign with my dad, mom, cousin Dishon and brother Ja'Waun at the 2004 MS Walk in Chicago, Grant Park

MICHAEL CRYSTAL AND BENJAMIN
S' MYELIN KIDS



WHEN I HAD AN EAR INFECTION LAST MONTH, I TOOK MEDICINE AND IT WENT AWAY IN A COUPLE OF DAYS.



YEAH, WOULDN'T IT BE GREAT IF ALL YOU NEEDED TO DO WAS TAKE SOME MEDICINE AND MS WOULD JUST GO AWAY?



I BET MS RESEARCHERS DREAM THE SAME DREAM WE DO!



PARENTS' PULL OUT



REASONS TO BE HOPEFUL FOR A CURE



The National MS Society:

- ◆ Currently spends \$35 million annually, for over 300 MS investigations.
- ◆ Has invested a total of \$460 million since the first three grants in 1947.
- ◆ Meets the standards of ALL major agencies that rate non-profit groups and funds more MS research than any other voluntary agency in world.
- ◆ Funds high-risk pilot grants, unique one-year grants to support research on innovative ideas.
- ◆ Is far-sighted, offering research and clinical fellowships to attract and keep the brightest minds in MS research.
- ◆ Offers a \$1 million cash prize (Ralph I. Straus Award) to any scientist(s) whose research leads to the development of a way to prevent or arrest MS.

- ◆ Offers the John Dystel Prize annually for the best research in MS.
- ◆ Sponsors MS-related workshops for the worldwide research community to encourage cross-pollination of ideas.

Ten years ago, we did not have any way to affect the progression of MS. Now we have several treatments that work for many people. We understand more about the mechanisms underlying MS and how to alter these processes.

In addition, the National Institutes of Health (funded by your tax dollars) spends approximately \$100 million per year toward research related to MS.

MULTIPLE SCLEROSIS NUMBERS
Prevalence, U.S.: 400,000 people
Prevalence, Worldwide: 2 million people



MY CHILD LIKES TO PRETEND SHE IS A SCIENTIST AND HAS INVENTED A CURE FOR MS. IS THIS HEALTHY BEHAVIOR?

According to psychologists, fantasy play and make-believe are vital parts of childhood development. In this essential stage, children engage in pretending and fantasy play in order to ponder and absorb important information and attempt to gain mastery over complex feelings.

Children don't often feel as though they have a lot of control over their lives; in pretend play, however, a child can be the person who takes care of others in need, saves the day, or finds the cure for MS. In other words, make-believe can help a child feel stronger. That may be

why children like to impersonate superheroes, parents, or doctors. Role-playing offers a chance to work out feelings of helplessness and gain a sense of power or control.



Your child's pretending to have found a cure for MS may reflect her deepest wishes, while also enabling her to feel in greater control of the feelings she has about MS. Encourage her to share her fanta-



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.

ND
MS.
R?

sies with you. If you have concerns that your child cannot distinguish her fantasy from reality, or, if you detect anxiety or worries that seem excessive, you may wish to

discuss the situation with a counselor. More likely, she is engaging in age-appropriate behavior that is helping her cope with the challenges of MS in your family.

Also, many future careers are born in the fantasy play of children and their personal experiences. Perhaps your child will be inspired to pursue medical research or clinical care in his or her future!



KEEP S'MYELIN is available on line at www.nationalmssociety.org
You can e-mail us at: keepsmyelin@nmss.org



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WE WANT YOU!

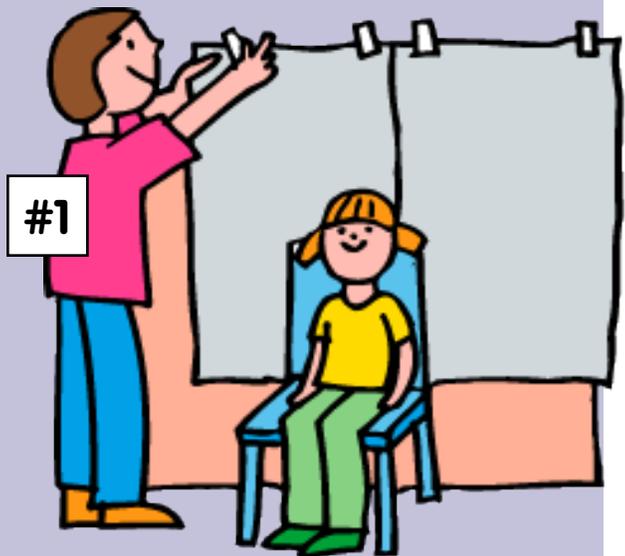
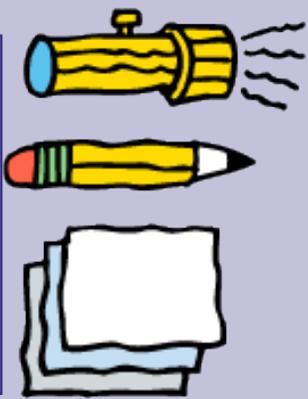


We love to publish your articles, stories, illustrations, poems, and interviews about MS. Please send us your work! Tell us how your family learns about MS together, how you feel about having MS in your family, what advice you would give other kids about having a mom or dad with MS, how you help your mom or dad, and whom you talk with about MS.

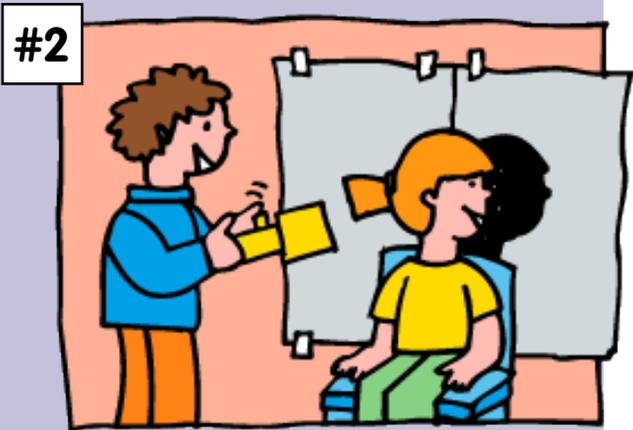
Send your stories and pictures to: KEEP S'MYELIN, NMSS,
700 Broadway, Suite 810, Denver, CO 80203
or e-mail them to keepsmyelin@nmss.org.

SILHOUETTE

- WHAT YOU WILL NEED:**
- Flashlight or small lamp
 - Large sheets of plain paper (butcher block paper works best)
 - Pen or pencil



1. Tape some large sheets of paper to the wall. Place a chair 3 to 4 feet from the wall so the chair is parallel.
2. Have someone sit in the chair. Have someone else hold the light up to the person's face so it forms a shadow on the paper.
3. Now trace the outline of the person's face on the paper.



You can then cut out the silhouette and decorate it, or leave it as is.





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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This issue is made possible by a grant from the Klein family in honor of Rona Klein, and by a gift from our New York City Chapter through the generosity of their sponsors, donors, and event participants.

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*The mission of the
National Multiple
Sclerosis Society is to
end the devastating effects
of multiple sclerosis.*