



Keep S'myelin

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

Who's on Your Team?

In this issue of Keep S'myelin is all about **teamwork**. Just like players on a soccer or baseball team need to work together, there are many people working together on the MS team—including you! The MS team is doing everything it can to find a cure and to help people live more comfortably with MS in the meantime. As you read this issue with your mom or dad, think about the teammates you know—like your family, teachers, friends, and the National MS Society—and the teammates you don't know—like doctors, scientists, and politicians.

What are all these team members doing to beat MS? **The scientists** are working in their laboratories to find out what causes MS and how to cure it. **The doctors, nurses, and rehabilitation experts** are helping people like your mom or dad to manage their symptoms and be as healthy as possible. **People in government** are passing laws to assist people with disabilities. **The National MS Society** helps people learn how to live with MS and raises money for research. **You and your family** are taking care of each other every single day. And **your friends and teachers** are there when you need some extra smiles and support. It's good to know that no one living with MS is alone.



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."



MS research is moving faster than ever before. Every day scientists are getting closer to the answers we need to important questions.

What causes MS?

What can cure MS?

What can prevent MS from happening to someone else?

We are finding answers more quickly because scientists from all over the world are starting to use teamwork. They are putting **their heads together** and sharing information. **Computers** help them talk to one another about their ideas and the results from their experiments. They can give each other help without having to be in the same place! Just like the teamwork it takes to score a goal in soccer or build a skyscraper or send a man to the moon, it takes teamwork to find the answers to MS.

interview with



CRISTINA



Cristina is 14 years old and a freshman in high school. She lives in Everett, Massachusetts, with her aunt and her dad, who has had MS since Cristina was born. Cristina has a brown belt in karate and is a cheerleader at her school.

KS: How does MS affect you and your family?

Cristina: My dad has had MS for a long time, but lately it has gotten worse. So, he can't do many of the things he used to be able to do without the help of his family. I felt worried when he started to get worse. I try to make sure I get everything done and done right, like keeping my grades up, helping him out, and trying to deal with the situation as best as I can. It's stressful for me.

KS: Who are some of the people who help you and your family cope with MS?

Cristina: ♦ My English teacher: He is almost part of my family! He has really

helped me and he encouraged me to call the MS Society. That's where I got some copies of Keep S'myelin and I also got some other books about MS that are really helpful for people like me who are trying to cope with this illness. He is someone I can talk to about how I feel.



♦ My three best friends: They are always there for me. I can let out all my feelings with them and they also will come over and help me with chores and taking care of my dad so it will give me a break! But even though they are always there for me, they can't always know how it feels to see someone you love have a hard time.

♦ My neighbors across the street: I've known them my whole life and they help us out. If my dad falls, they come over and help get him back up.
♦ My grandmother: She comes over during the day to help my dad. But I help out after school and in the evenings.

KS: What advice would you give other kids who have a mom or dad with MS?

Cristina: ♦ **Don't hold in your feelings.** Talk about them or write about them. I write poetry about how I feel. It's interesting to look back on some of the poems I wrote a while ago. I can see that things can progress and get better!
♦ **Make time for yourself.** Make time for yourself to just be a kid!

♦ **Don't give up!** Find someone to talk to if you feel stressed and think about the good things in your life!

The MS Team

In addition to your family, there are many people in your life who help you every day! Everyone plays an important part on your "MS Team."

Write the names of some of your team members on the lines below.

YOUR TEACHER:
listens to you
and answers
your questions.



YOUR FRIENDS:
have fun with you.

THE NATIONAL MULTIPLE SCLEROSIS SOCIETY:
helps you and your family learn about and meet other families.

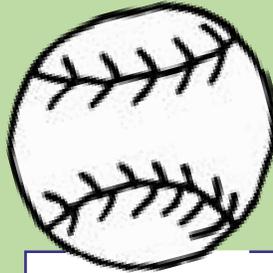
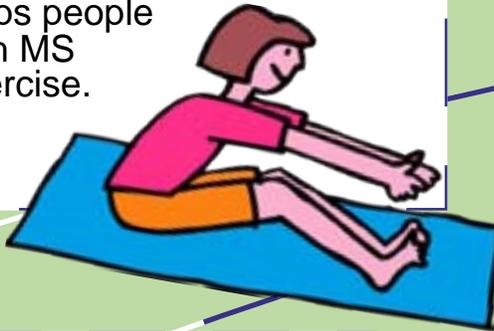


MS RESEARCHERS:
work to find a cure for MS.



My 'MS Team'

PHYSICAL THERAPIST:
helps people
with MS
exercise.



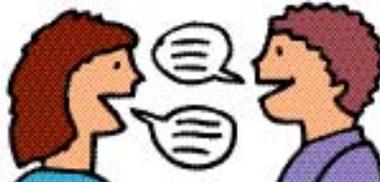
SPEECH THERAPIST: helps
people with MS if they are
having difficulty talking.



NEUROLOGIST: takes care
of people with MS.



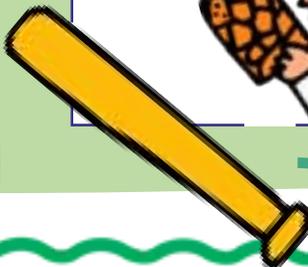
COUNSELOR: helps families talk
about MS together.



OCCUPATIONAL THERAPIST:
helps people with MS
learn how to do day
day activities
more easily.



NURSE: helps people with MS
learn about taking medicines
and how to be as healthy as
they can be.



Letter to KS

Dear KS:

I worry when my dad has to go to the hospital. How do I know he'll be OK?



KS: Worrying about the people you love is normal. When you have lots of worries it helps to talk to an adult about them. An adult, like your mom or dad, another relative, or your teacher, can help you understand why your dad is in the hospital, what kind of treatment the doctor is planning to give him, and when he'll be home again. Understanding more about MS can help you worry less, and talking about your feelings can help you feel less afraid or angry or sad. Ask if you can visit your dad. Seeing him will help you feel better, too.

AJ'S TEAM



Ten-year-old AJ, who lives in Pennsylvania, has an uncle with MS. AJ is using teamwork to help raise money for MS research. AJ competes nationally in motocross events. He decided to use his love of the sport to raise money. He and his family and friends planned a day at a motocross racetrack. AJ completed 100 laps. Family, friends, and other people in the community pledged money for each lap. AJ and his team of volunteers have been very successful in raising money for MS research. Congratulations to AJ and his team!

JOKES

What sound do porcupines make when they kiss?



Ouch!

What do you call a sleeping bull?



A bull-dozer

What do dogs eat at the movies?



PUP-CORN



MICHAEL CRYSTAL AND BENJAMIN
S'MYELIN KIDS



IT'S BEEN BUSY AT OUR HOUSE TODAY. MY MOM'S PHYSICAL THERAPIST CAME OVER TO DO EXERCISES WITH HER. THEN OUR NEIGHBOR HELPED MY MOM ORGANIZE HER OFFICE, AND MY SISTER AND I DID THE LAUNDRY.



GEE, WHEN EVERYONE HELPS, THINGS REALLY GET DONE!

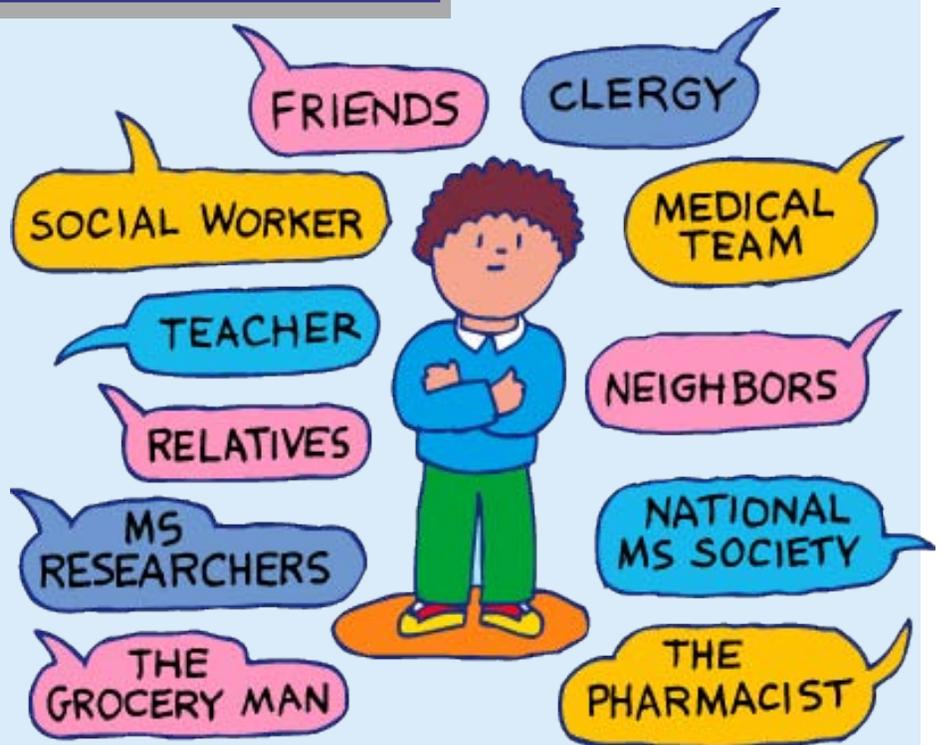
IT'S JUST LIKE A TEAM. EVERYONE PITCHES IN AND EVERYONE WINS!



PARENTS' PULL OUT

This issue is designed to reassure your children that there are lots of people who can help your family cope with MS. The medical team, friends, neighbors, teachers, clergy, relatives, the social worker, the National MS Society, MS researchers, the grocery delivery man, the pharmacist.....all may be members of your family's "team." In the same way "it takes a village to raise a child," it may be helpful to talk to your children about the community of people who care about you and care about them and can help your family deal with any challenges MS may pose along the way.

As you read this issue together, have your children name the people in their life who are on their "team." The con-



versation could include the many people in your family's life that support and love your family, whether it has anything to do with MS or not! Reminding your children of the special people he or she can talk to, ask for help, have fun with, and rely on, can be reassuring and empowering.

Talk to your children about how they are important members of your team. Remind your children how much they contribute by helping out at home, spending quiet time with you, working hard at school, and making you proud of how nicely they are growing up.

FAMILY

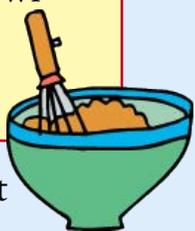
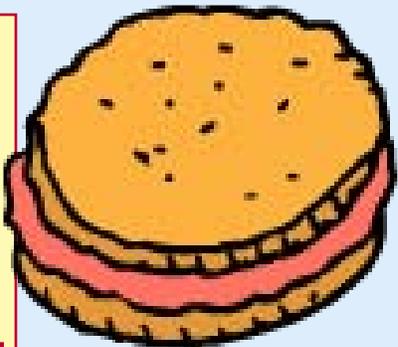
RECIPE

"ICE CREAM" SANDWICHES

YOU WILL NEED:

- ◆ 1 1/2 cups cold milk
- ◆ 1/2 cup peanut butter
- ◆ 1 package instant chocolate or vanilla pudding
- ◆ 24 graham crackers or chocolate wafers

- ◆ One large mixing bowl
- ◆ A cookie sheet
- ◆ Wax paper
- ◆ Hand mixer



- ◆ Line the cookie sheet with the wax paper.
- ◆ Spread 12 graham crackers or wafers on the cookie sheet.
- ◆ Add the milk to the peanut butter and blend until smooth.
- ◆ Next add the pudding mix and beat at a low speed for two minutes.
- ◆ Let the mixture stand for five minutes.
- ◆ Spoon 1/2 inch of mixture onto each graham cracker/wafer. Spread to the edges of the cracker.
- ◆ Top each cracker with one cracker.
- ◆ Freeze until firm; about 3 hours. Makes 12 sandwiches.

THE GREAT ESCAPE

(from Escapades © 1996)

SURVIVOR MEETS YOUR FAMILY!



You and your family are trapped in a large forest. Your food is almost gone. The nearest town for your own safety is 20 miles away. Your family need to overcome the challenges.

- ◆ Break out of the thick woods
- ◆ Get around a 20 foot smoky fog
- ◆ Get through a heavy barbed wire fence
- ◆ Cross a very fast moving river
- ◆ Travel through the heavy rain

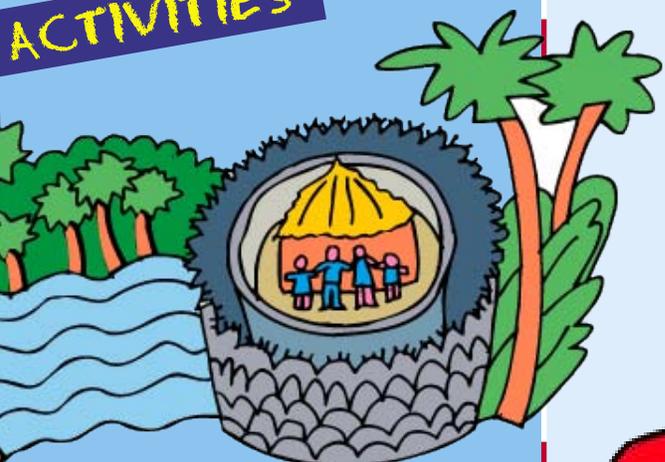
Your job as a team (you and your family) is to find three things that would be useful to escape. These things are all you have to escape the forest. Use your magical devices (such as a laser sword, a magic wand, etc.) Good luck!

NOTE: (There is no right or wrong answer. Rather, it is a way for your family to work together.)

FUN

PICTURE

ACTIVITIES



PUZZLES



in a hut in the middle of a
gone and you have to reach the
. To reach the town, you and
ese obstacles:

- lled hut
- ooth wall
- ed wire fence
- river
- and dense forest

ur family) is to come up with
l in your escape – these three
! You cannot use helicopters or
sword.) Now plot your escape.

ong to the solution to this game.
ly to problem-solve, laugh, and

Here's a great idea for your box of pictures! You will need a scissors and old photos that have doubles or that you don't want to keep. Cut the pictures into several different shapes and sizes (a few pieces for little ones and lots for older kids). The fun starts when you try to put the pieces back together! To make the pieces easier to handle, mount them on cardboard. You can also store them in individual zipper bags for later use.

PARENTS' PULL OUT

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



**How Can You
Subscribe
To Keep
S'myelin?**



**Call 1-800-FIGHT-MS.
(1-800-344-4867)**

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,
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or e-mail them to
keepsmyelin@nmss.org.**



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ISSUE #17
Keep
S'myelin

TEAM WORK

The National MS Society...One thing people with MS can count on.



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.*