

Keep S'myelin

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

THIS IS ABOUT YOU!

Most of the articles, drawings, and stories in this issue of Keep S'myelin were written by you. Thanks for sending us your wonderful work. If you would like to write a story or poem for Keep S'myelin, please send it to:



Jennifer Ricklefs,
Keep S'myelin, NMSS
700 Broadway, Suite 810
Denver, CO 80203.

We welcome your contributions! You might see yourself in print some day! Writing about MS in your family, or drawing pictures that tell a story about MS in your family, are great ways to share your

ideas and feelings. You don't have to be a famous artist or poet or author to draw, write poems, and tell stories.

Share your work with your parents or other grown-ups, such as your teacher, a friend, an aunt or uncle... They want to learn about how you feel about MS. Sharing your work gives you a chance

to talk over things that might be confusing about MS, or that might be funny or sad or frustrating about MS. Sharing may make you feel better, too!

WE LOOK FORWARD TO RECEIVING YOUR STORIES, AND POEMS, AND DRAWINGS.

M.S.

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."

E Y E S OF A C H I L D

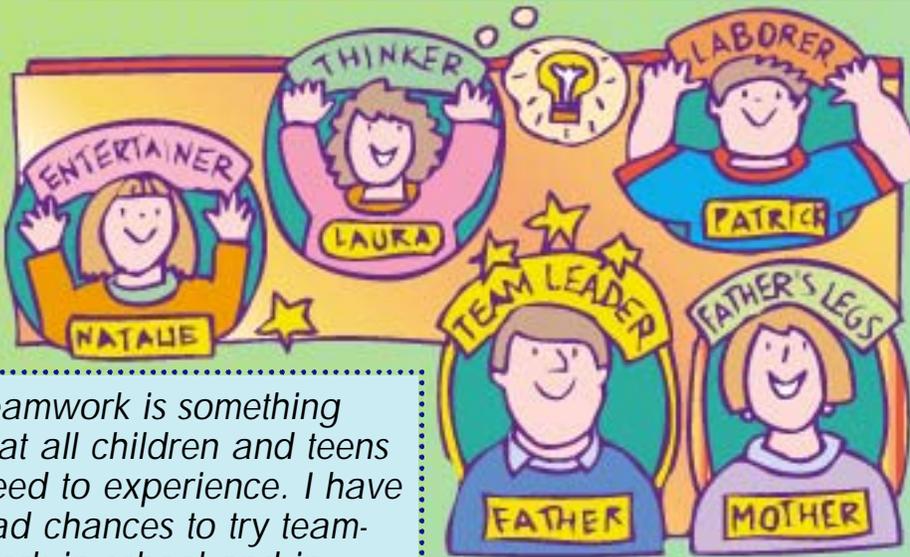


CAROLINE
Age 10
New Jersey

How TEAMWORK

Has Already Helped Me Succeed

NATALIE
Age 14



Teamwork is something that all children and teens need to experience. I have had chances to try teamwork in school and in sports and it has given me a boost in life. But the one team that means the most to me is my family. In my eyes, we work together better than any other family.

Ten years ago, my father was diagnosed with multiple sclerosis. Back then when I was only four or five, it wasn't too bad. But now, as the days and years go by, my father's legs are hardly able to balance him anymore, his eyesight is not great, his writing is sloppy, and at times he even gets tired of thinking!

Each member of my family plays a different role in helping to make our family life better. I have taken into my own hands the responsibility of entertaining my father! I play soccer and my father loves the sport as much as I do! I would never quit because I see the joy in my father's eyes when he sees me play sports. My mother takes the role of being my father's legs. Whenever my father needs something, she does the walking. My sister, Laura, plays the role of thinker.

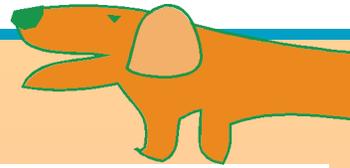
My father always had a lot of ideas and thought about ways to get jobs done with a high intelligence level. When my sister comes home from college, she does some of the thinking jobs that are harder for him now. My brother, Patrick plays the laborer. He has the physical strength to do all the jobs that contain the hard work.

Finally, my father's role on our team is the team leader. He is the strongest member of the team. He rarely lets his MS get him down. He's always there when you need him. He's taught us how to have a positive attitude and appreciate the good life.

Having MS in our family has taught us things that nothing else could ever teach us. I am lucky to be a part of such a meaningful team—my Dad's team.



CASEY



CASEY is a 6th grader in Middle School in North Carolina. She likes to read and draw, and she has lots of pets : a horse, a bird, 5 dogs, and a goat! Her mom has had MS for 2 years. Casey wrote and illustrated this story for Keep S'myelin.



1

Momma has Multiple Sclerosis... but everyone calls it "MS". This disease has to do with the NERVOUS SYSTEM. My name is Casey, and I'm going to tell you about this disease. But, first, I will introduce my family. Tom is my stepdad. Brittany is my little sister, and Tammy is my momma. Our pets: Cuervo, Dixie, Chad, Riley, Max, Ginger, Blossom, Danzig, Jasper, Smokey, Fancy, Buster, Streak, and Penny. All of those animals were our horses, dogs and cats. Well, here goes...

Sometimes, MS makes momma lose her balance, and almost fall. That's why she has to use a cane or hold my sister's, mine, or Tom's hand. One time, in a store, she had to use a wheelchair.

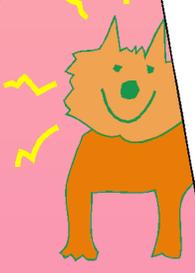


4

Sometimes, momma talks blurry. It's kind of like a tongue twister to her.



5



MS gives momma double vision. She has to wear sunglasses when she drives, which is rare.



2

Well, this is Tom. He takes good care of our family. He is a dog trainer and makes a lot of money. He also gives momma her shot every Sunday.



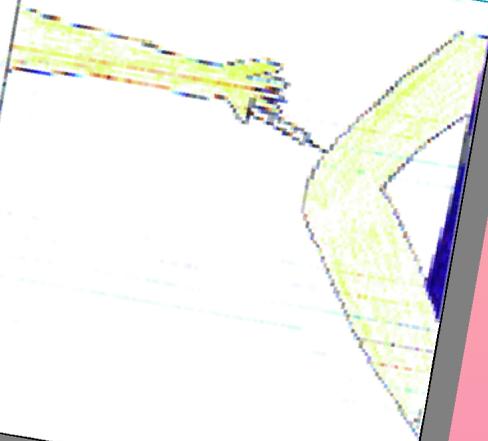
3

Momma has Multiple Sclerosis, but her family doesn't give up on her 'cause they love her. We always will.



7

Tom gives momma a shot every week, on Sunday. Brittany holds momma's hand, so momma can squeeze it. She also tells momma to think of sunflowers and fairies.



6

Now you can send us your stories, poems, and comments by e-mail! Keep S'myelin can be reached at:

KeepSmyelin@nmss.org

We asked our readers: How would you help other kids deal with their feelings about MS?

You sent us lots of very good ideas. Here are some of your replies.

Our readers are really smart!



Here are Some Tips for You!

I would tell other kids: "Don't be afraid of MS (your parent's or anybody's). They are still regular humans!"
CR, Pennsylvania

I would say: "Let out your feelings! And exercise!"
TR, New Jersey

I would say they should not worry. It will be OK.... Well, they can worry a little bit, but not too much!
SA, Ghana, West Africa

I would tell them that I deal with the same feelings.
TS, Wisconsin

I would just say that you have to love your parents whether they have MS or not!
BM, Wisconsin

I would say: "Just be happy and make sure you always love the person with MS!"
MS, Oregon

I would talk to my friends about it and ask them how they feel.
DD, South Carolina

I would tell them to write to Keep S'myelin and ask questions so they can feel more comfortable!
KH, Ohio

I would help my friend by saying, "It will be OK, my friend."
AH, California

I would tell them to just pray to God and He will help them in their troubles.
SS, Bermuda

I would tell them to try to forget it's there most of the time. But don't put it totally out of your mind at all times, because your mom or dad still needs your help!
SM, Pennsylvania



Q: What is a cow's favorite lunch meat?
A: Bull-ogna

Q: What do cows get when they are sick?
A: Hay Fever

Q: Why does a milking stool have only three legs?
A: Because the cow has the udder

Q: What do you call a cow that just recently had its baby?
A: De-calf-inated

POEM

My mom is sweet.
My mom is neat.
My mom has MS.
Her younger kid is Tess.
I really think I have a mom
Who can't be beat!

Shane (Connecticut)
8 years old



HERE IS ONE WAY TO WRITE YOUR OWN "PLAY ON WORDS"

TRY THIS



Some jokes start by using a word or phrase that has two different meanings. Here are some tips for writing your own "play on words" jokes.

- 1 Find a word or phrase with two meanings. *Example: Digs rock*
- 2 Write down the two meanings in sentences. *Example: A bulldozer digs rock. A musician digs rock.*
- 3 To make your joke, ask why the two things are like each other. *Example: Why is a bulldozer like a musician? They both dig rock.*



Here is a list of words that have two meanings. You can use these or other words to make up your own jokes or try some other words. Go ahead! Tickle your funny bone.

PEN

BILL

DUCK

RIGHT/WRITE

RING

SAW

Keep S'myelin wants to hear from you. Send us your favorite jokes so we can include them in our newsletter. Or create your own new jokes and share them with us.



KEEP S'MYELIN

PARENTS' PULL OUT

This issue of **Keep S'myelin** is filled with artwork and stories by children who have a parent with MS. Their creative variety reflects the variability of the disease itself, providing you with the opportunity to remind your child(ren) that every person's MS is different. Some people with MS have symptoms that no one can see from the outside, while other people may need to use one kind of assistive device or another to do the things that are important to them. Regardless of their parent's disability, however, the message from these young artists is clear: Mom or Dad is there to love and take care of them.

As you read and talk about this issue, you and your child(ren) might want to draw pictures of your own family and

HOW TO READ



KEEP S'MYELIN WITH YOUR KIDS

the special things you like to do together. This is a good opportunity to talk about your own symptoms and the ways you—and they—have adapted to the changes MS has brought into your lives. Decorating a cane or other assistive device can set the stage for talking about their concerns about MS and the symptoms it can cause, while emphasizing the value of tools in our everyday life. Natalie's story about her family's teamwork may

suggest ways for each member of your family to be an active player on your MS team.

You may find yourself startled—or even hurt at times—by your child(ren)'s reactions to your MS. They may laugh at a symptom that looks funny to them, get angry about your inability to do something for or with them, or simply act as though there's no problem at all. In other words, their feelings may seem to be totally out of synch with your own. The stories and drawings in this issue offer the opportunity to talk with your kids about how each of the people in a drawing might be feeling. This is a great way to share feelings and worries about MS, see things from different perspectives, and remind yourself and your children that everyone's feelings are unique.

INVISIBLE INK



- WHAT YOU NEED:
- Juice of one fresh lemon
 - A thin paintbrush
 - White paper

Write a secret message to a friend or family member! It's very easy. Here's how to make your own invisible ink.

3 TO READ IT, hold the paper near a light bulb or place it out in the sun. Your message will appear as brown writing.

DIRECTIONS

1. Squeeze the juice from one fresh lemon. (You may need the help of an adult.)



2. Dip your paintbrush in the lemon juice and write your message.



How Can You Subscribe to Keep S'myelin?



CALL 1-800-FIGHT-MS.

You will be connected to your local 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 local chapter.

If your child is submitting something to Keep S'myelin, be sure to include the PARENT'S NAME, ADDRESS, AND PHONE NUMBER.

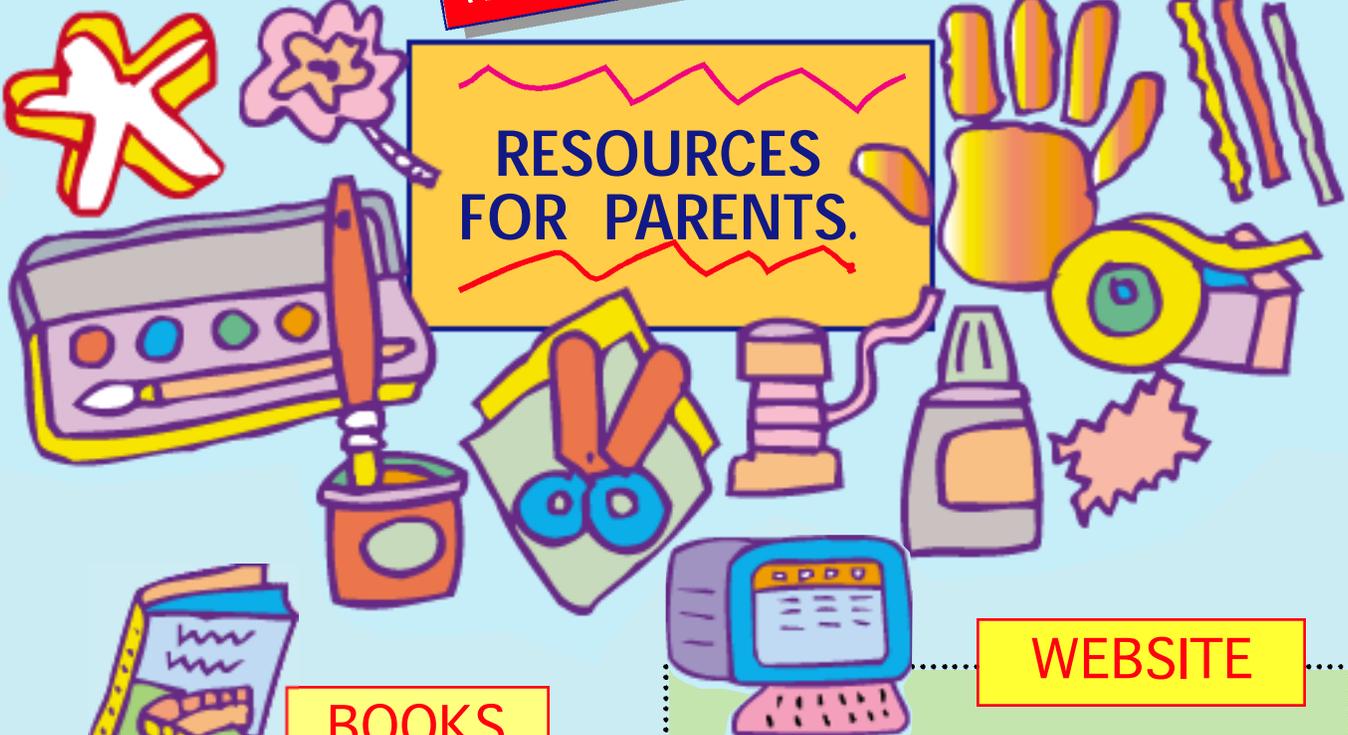


KEEP S'MYELIN is now available on line at www.nationalmssociety.org



PARENTS' PULL OUT

RESOURCES FOR PARENTS.



BOOKS

IDEAS FOR ART AND PLAY WITH YOUR CHILD

EVERYDAY ART FOR KIDS
Projects to Unlock Creativity
by Carolyn Holm

KIDS CREATE!:
Art & Craft Experiences for 3- to 9-Year-Olds
by Laurie Carlson

ART IS A WAY OF KNOWING
by Pat B. Allen
(Good ideas for projects using art to help express emotions)

WEBSITE



GET CRAFTING with this link to all kinds of activities you can explore and share with your child.

<http://www.kidsartscrafts.about.com>

NOTE:
If you notice disturbing themes in your child's art work over time (e.g., intense sadness, anger, violence...), consider talking with a counselor or teacher about ways to help your child further explore his or her feelings.

As of the printing of this newsletter, all phone numbers and web addresses were accurate. These are subject to change, however. If you discover an inaccuracy, we encourage you to check with Directory Assistance or an internet search engine.



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** and funded by a grant from our **Gateway Area Chapter**. 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.

The National Multiple Sclerosis Society does not endorse products, services, or manufacturers. Such names appear here solely because they are considered valuable information. The Society assumes no liability whatsoever for the contents or use of any product or service mentioned.

Editors

Jennifer Ricklefs, MS
Debra Frankel, MS, OTR
Rosalind Kalb, PhD

Advisors

David Rintell, EdD
Vicki Dodge-Pamplin, CIR
Shannon Stapleton, MSW
Kevin Dougherty, MA
Debbie Wall, MPA
Deborah Miller, PhD
Elly Schottman
George Garmany, MD

Design/Illustrations

Claude Martinot Design

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

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

