

# Keep S'myelin

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

Hi, we're Michael, Crystal and Ben

AND  
EACH  
OF US

HAS  
A  
PARENT

WITH MULTIPLE  
SCLEROSIS  
(MS)

M

C

B

**I**f you just found out that your mom or dad or someone else you know has multiple sclerosis, or even if they've had it for a while, you probably have lots of questions. You're not alone! Lots of kids have questions about MS. Multiple sclerosis is hard to say and spell, and really hard to totally understand! This newsletter is for you. It will help answer some of your questions. It may also help you to talk with your family and friends about the changes multiple sclerosis can bring.

**I**n each of the Keep S'myelin newsletters you will find:

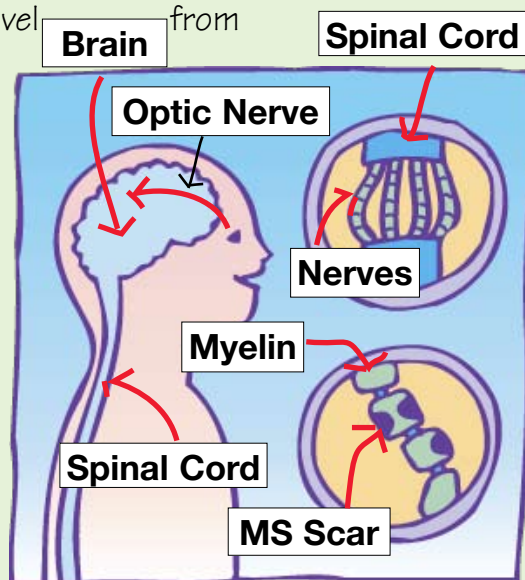
- Information on MS
- Puzzles, games and fun activities
- Ideas to talk with your parents about
- And ways to tell us what you know and think about MS

# What is MS?

MS is a sickness that affects the central nervous system (the brain, the nerve that connects the eye to the brain, and the spinal cord). The brain is like a computer that sends messages to the body telling it what to do. The spinal cord is like a thick cable of wires attached to the computer. Messages travel from the brain, along the spinal cord, to the muscles and other parts of the body. If the brain wants the fingers to wiggle, it sends a message along the spinal cord out to the arm and down to the fingers, and they wiggle.

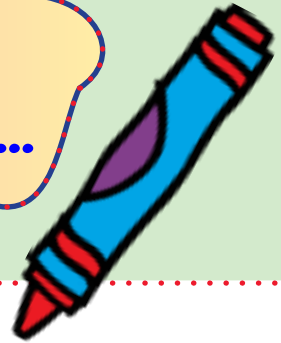
When a person has MS, the covering or coating (called myelin) that protects the nerves in the brain and spinal cord gets damaged. Myelin works like the rubbery coating around electrical or phone wires. When wires on a telephone lose their coating, the sound gets crackly.

As messages travel from the brain, they sometimes get stuck or slowed because the myelin is damaged. When this happens, muscles or other parts of the body can't always do what the brain is telling them to do.



**MULTIPLE** means many.  
**SCLEROSIS** means scars.  
Multiple sclerosis means many scars.

This is HOW  
I imagine  
MS might look...



# LET'S HA

## Lunch Bag



### WHAT YOU WILL NEED

- Paper lunch bags
- Glue
- Magazines
- Yarn

**T**his is a fun activity for the whole family! Each person gets to create a puppet using a paper lunch bag and anything you have around the house. You can use pictures from magazines, yarn, buttons – whatever you have handy. Your puppet can be a person, a tree, a flower – let your imagination go wild. After your puppets are done you can have a puppet show.



# HAVE FUN

## 9 Puppets

### NEED:

- Crayons & markers
- Other decorating materials (buttons, glitter, cotton balls, fabric, etc.)



What gets wetter and wetter each time it dries?

A towel!



Why did the Grizzly bear catch a cold?

He went outside in his bear feet.



Q: What game do cows play at parties?

A: Moosical chairs.

# READER SUBMITTED

## STORIES

### SALLY'S STORY

My mom has MS. Sometimes it's hard having a mom with MS, but I know that she needs my help. I love my mom a ton. On vacation we have fun in the sun. Me and my brother think MS can be a bother, but I love my mom for who she is and I hate MS for what it is.

### AMAYA'S STORY

Hi. My name is Amaya and I am 5. My mommy found out she had MS while I was in her tummy. Sometimes she can walk and sometimes she cannot. When she can't walk, we both ride around on her scooter and I think it is fun. I try my best to take very good care of her and help her out around the house. She is my only mommy and I love her so much, no matter what.

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

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](mailto:keepsmyelin@nmss.org).

We love to publish your pictures, stories, poems, and interviews about MS. Please send us your work! You may want to tell us how you feel about having MS in your family, what advice you have for other kids with a mom or dad with MS, or whom you talk with about MS.



## Let's Meet some People with MS

To help you learn about some of the ways MS can affect people, we would like you to meet some friends. You will notice that MS affects each of them in different ways:

### LYDIA

works in a laboratory. She is a researcher and is discovering ways to make new medicines. She uses a scooter because her MS makes it very difficult for her to walk or stand. She also gets very tired from her MS, so she takes a nap at lunchtime and again when she gets home from work. Lydia's lab has extra wide aisles so she can get around easily in her scooter, and she has an easy chair in her office so she can rest.



### KATHY

is the receptionist in a dentist office. She welcomes the patients and makes sure everything runs smoothly. Kathy sits behind a big desk in the waiting room. Her MS has caused problems with her balance so she uses a cane to help her walk. Her fingers sometimes feel a little clumsy, so she uses a computer with a very big keyboard. That helps her avoid making typing mistakes!



### CARLOS

is a stay-at-home dad. He takes care of his children, ages 6 and 9, when they come home from school. He helps them with their homework and makes dinner for the family. He used to work in a factory, but his MS made it too hard for him to use his tools safely. He uses a wheelchair around his house. He misses working in the factory sometimes, but he feels lucky to spend so much time with his children.



# KEEP S'MYELIN®

## PARENTS' PULL OUT

# WELCOME

## TO KEEP S'MYELIN

A newsletter for kids about multiple sclerosis. Every issue will include a Parent's Pullout section with articles on family-related topics, recommended resources, parenting tips, and suggestions for ways to share individual articles and activities with your children.

### OUR GOAL

When one member of a family has MS, it is important that the entire family learn how to live with it—and finding comfortable ways to talk about MS can be an important step in that process. Our goal is to provide children with accurate information about a complicated disease, in a format that is easy to understand and fun to use.

### EACH ISSUE

of *Keep S'myelin* will focus on a particular issue related to MS. In addition to stories written by specialists in the field of MS, there will be:

- Puzzles, games and activities for your children to do with you or on their own.
- Answers to commonly asked questions.
- An opportunity for kids to send in their own pictures, stories, and questions.

### KEEP S'MYELIN

is written for children ages 5 to 10. The games and activities in each issue are designed to help kids understand MS, become more familiar with important words and concepts, talk about the disease more comfortably, and learn how to live with it in their family. The newsletter will also help families get acquainted with the National MS Society and come to see it as a source of information and support.



# HOW INFORMATION ABOUT MS HELPS CH

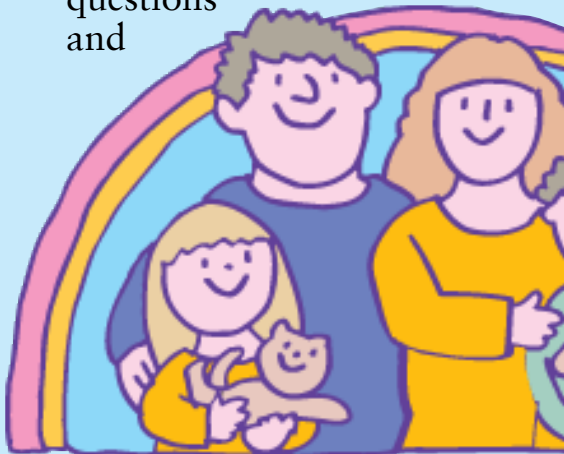
Parents often wonder how much to tell their children about MS. They worry that talking about the MS will be too frightening, too confusing, and too burdensome for the kids to handle. They don't want their young children to have to deal with Mom or Dad's MS "until they are older." In our experience, however, children with a parent with MS are already dealing with the impact of the disease, whether or not it is being talked about openly in the household. This is because kids of all ages have a remarkable ability to sense what is going on around them, particularly when it affects their parents. They can tell when their parents are worried, upset, preoccupied, or feeling tired or blue.

We wanted to make this newsletter available for children because we feel that accurate information, geared to a child's age and abilities, helps that child to understand and cope with changes MS may bring. Information is helpful in some very specific ways:

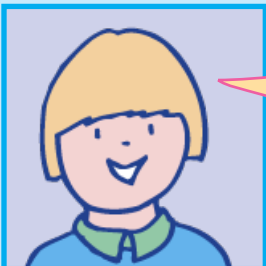
- Without any information to explain the changes they sense going on around them, children use their imaginations to fill in the blanks. Often, the things they imagine are far worse than reality.
- Younger children tend to see events in their lives as connected to their own actions. This way of thinking sometimes leads children to believe that they may have caused their parent's MS, or caused it to worsen.

Accurate information about MS reassures them that they have not caused their parents to get MS and helps eliminates any guilt they may be feeling.

- Kids often have no idea how to express their questions and



feelings about MS. Keep S'myelin provides them with the vocabulary they need to share their concerns. By reading this newsletter with your children, you are also reassuring them that it is okay for them to talk to you about MS.



KEEP S'MYELIN is available on line at [www.nationalmssociety.org](http://www.nationalmssociety.org)  
You can e-mail us at: [keepsmylelin@nmss.org](mailto:keepsmylelin@nmss.org)

CHILDREN

ENJOYING  
KEEP S'MYELIN  
WITH YOUR KIDS

• Information about MS, and about other families who are living with it, assures children that they are not alone. Through this newsletter, they will read about other kids who share similar experiences.



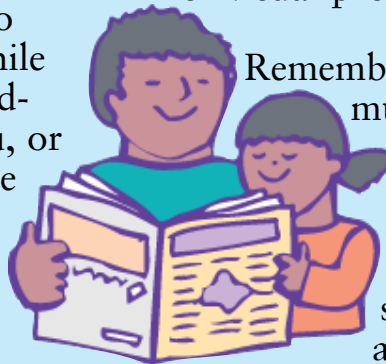
As you know, children learn in many different ways. One may like

Keep in mind that children have the hardest time understanding the symptoms they cannot see — like fatigue or visual problems.

• When you share important information about MS and your efforts to cope with it, you are modeling the kind of openness and communication that parents and children need to have in today's world. As a result of your openness, they will be more likely to share with you the issues that come up in their own lives.



to read or do activities alone, while another enjoys reading aloud with you, or playing games. One might have lots of questions for you while another asks nothing at all. The articles and activities in *Keep S'myelin* can be used in any way that is fun and comfortable for your children and you. As you read the features in this issue, you may think of things you would like your kids to know about your MS. You might find it helpful, for example, to read "Let's Meet Some People with MS" together and compare your symptoms with the symptoms described in the article.



Remember that too much information at one time can be overwhelming, so try to answer only the question they are asking. When they're ready for more, they'll ask. There may be times when some questions may be difficult or upsetting for you to answer. The staff of your chapter of the National MS Society is available to provide the emotional support you and your family may need, as well as information, and additional educational materials.

You can contact your chapter by calling 1-800-FIGHT MS (1-800-344-4867) or by visiting [www.nationalmssociety.org](http://www.nationalmssociety.org).

**PARENTS' PULL OUT**

## RESOURCES AND PUBLICATIONS



**National Multiple Sclerosis Society**  
1-800-FIGHT MS (1-800-344-4867)  
[www.nationalmssociety.org](http://www.nationalmssociety.org)

The mission of the National Multiple Sclerosis Society is to end the devastating effects of MS. The Society offers a variety of programs, services and resources for families.

**Through the Looking Glass** is a community non-profit organization serving families in which one or more members has a disability or medical issue.

**Publications and Periodicals**  
**Multiple Sclerosis: A Guide for Families (3rd Edition)**  
by Rosalind C. Kalb, Ph.D.  
Available through  
Demos Medical Publishing  
([www.demosmedpub.com](http://www.demosmedpub.com))

**Through the Looking Glass:**  
A National Resource Center for Parents with Disabilities,  
2198 Sixth Street, Suite 100,  
Berkeley, California 94710-2204  
1-800-644-2666,  
website: [www.lookingglass.org](http://www.lookingglass.org)

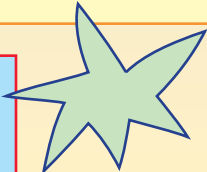
**Available through the National MS Society:**

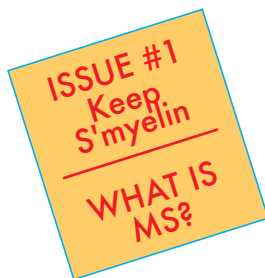
**Keep S'myelin: An Activity Book about MS for Kids**  
**Keep S'myelin Online**  
Interactive versions of this popular and award-winning publication are available at  
[www.nationalmssociety.org](http://www.nationalmssociety.org)

**When a Parent Has MS: A Teenager's Guide**  
by Diane O'Connell, with the Programs Staff of the National MS Society  
**Someone You Know Has MS: A Book for Families, adapted by Martha King**



**Teen Inside MS**  
A quarterly online magazine written by and for teens ([www.nationalmssociety.org/TeenInsideMS](http://www.nationalmssociety.org/TeenInsideMS)).





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



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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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This issue is made possible through the support of the following Program Honor Roll chapters: Central New England, Central Pennsylvania, Gateway Area, Greater Connecticut, Greater Delaware Valley, Greater Washington, Indiana State, and Mid-Atlantic.

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