



A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS

**L**iving with MS brings changes to every member of a family. Some changes may be big; others may be small. Some changes are easy to deal with. Others are harder and take longer to get used to.



brings. Be honest about how you are feeling. Whether you feel confident, sad, angry, or confused, it is important to share your feelings with your family, a teacher, or a good friend.

**B**ecause MS is different for each person that has it, different families deal with different changes.



MY DAD'S NOT ABLE TO PLAY OUTSIDE WITH ME.

- do more chores since your
- mom or dad got MS.
- Maybe your dad has started
- doing the laundry

because your mom is so tired from the MS. Or maybe your grandmother

- takes you to school
- because your dad is not
- able to drive anymore.

**M**any times, family members take on new responsibilities because of MS. For example, maybe you've had to



I AM MY MOM'S EXERCISE PARTNER BECAUSE EVERY DAY I HELP HER DO EXERCISES AND STRETCH HER MUSCLES.

- Each person in a family
- reacts in his or her own
- way to the changes MS

- **Y**our family members are
- able to love and support
- you whether or not they
- have MS. Remember,
- having MS in your family



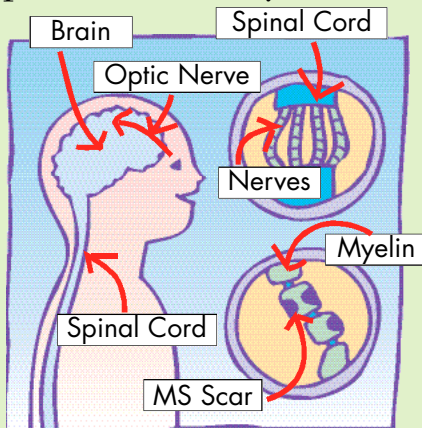
MY MOM AND I TALK TOGETHER AT NIGHT. WE PLAY WORD GAMES AND WE TALK ABOUT EVERYTHING!

- can strengthen your love
- for one another. Show it
- and share it.



# MS

**Multiple sclerosis (MS** for short) is a disease that affects the central nervous system (the brain, optic nerve 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,

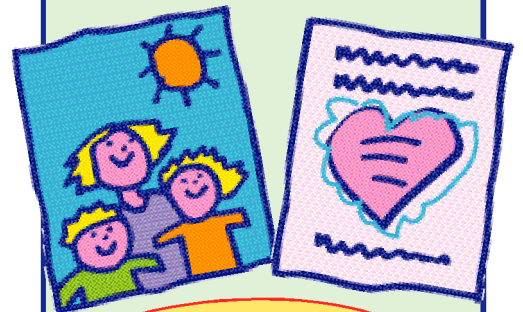
the other parts of the body can't always do what the brain is telling them to do.

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, and poems 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, or whom you talk with about MS.



Send to:  
**National MS Society**  
**KEEP S'MYELIN**  
900 South Broadway  
Second Floor  
Denver CO 80209  
or e-mail to  
[keepsmyelin@nmss.org](mailto:keepsmyelin@nmss.org)





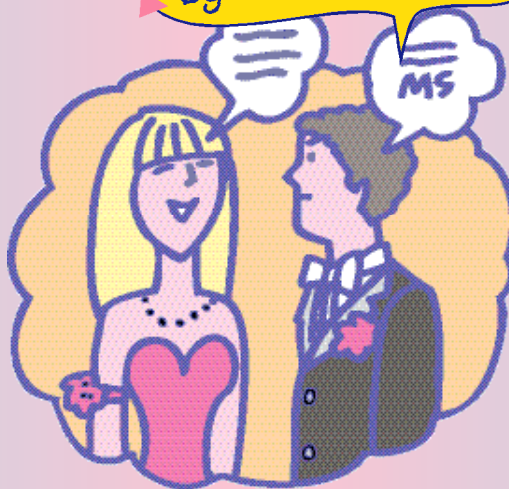
# JEREMY'S STORY

By Jeremy Spiegel

**M**y mom has had MS since I was ten. I always wished that my mom didn't need to use a wheelchair. I didn't want my family to be any different than those of my friends. I just wanted a healthy mother who could do all the things that my friends' mothers could do – drive me places, chaperone field trips, cook big dinners. (Of course, my mother will never win any cooking awards no matter what, but that's another story!)

I didn't always know how to tell my friends about my mother's illness. I felt strange talking about it because it's not something that just comes up while you're chatting about the latest movie or school project. Sometimes I would tell my friends and other times I chose not to tell until they met my mom for the first time.

Either way, it's normal if it feels a little weird telling your friends about your



mother or father having MS. After all, it's a very grown-up topic to talk about.

**H**owever, I now realize that everyone has something a little bit different about his or her family. When my prom date, Carrie, was going to meet my mom for the first time, I said casually, "By the way, my mother has MS and uses a wheelchair." She smiled at me and replied, "Oh really? Well, my dad's blind!" We both laughed because we each felt a little awkward at first, but then realized it wasn't that big of a deal. We each wanted the other to feel comfortable. If you don't make a big deal of it, your friends won't either.

**Y**our friends will want you to feel comfortable when you talk to them about your parent's MS. I'm sure that you'd want your friend to feel relaxed if he or she was confiding in you about something personal. Some friends asked me questions about MS (most kids don't know exactly what it is), but others didn't know how to ask me about it. I learned that both responses were normal.

**T**here's no right or wrong way to talk to your friends about your parent's MS. Just do it when you feel ready. Once you tell a good friend or two, you'll have someone else you can talk to. And that's a nice thing.



## We asked, You Answered...

HOW WOULD YOU HELP OTHER KIDS DEAL WITH THEIR FEELINGS ABOUT MS?



I would help them with their problems. I would draw them a picture.

Shelby (age 8)



Make cards and home-made gifts.

Nona (age 8)



I would play with them and tell them funny jokes.

Katherine (age 10)

Ask your mom or dad questions about MS and talk to people you trust. Don't get mad at whoever has MS because it is not their fault.

Colleen (age 8)



## JOKES



Knock, Knock  
Who's there?  
Olga.  
Olga who?

Olga home if you  
don't open the  
door!

Knock, Knock  
Who's there? Olive.  
Olive who?

Olive here!

Knock, Knock  
Who's there? Luke.  
Luke who?

Luke through the keyhole  
and you'll see!

What's the longest word  
in the dictionary?

Smiles, because it's a  
mile from one 's' to the  
other!

What gets wetter  
and wetter each time  
it dries?

A towel!



# FAMILY FUN TIME

These are some of the fun things we do together as a family:





S M Y E L I N K I D S





## MY FAMILY

EIFIQF SCUSUR  
TMQTCBFUWS SRGNIKLATW  
IOSGUHIFEWNR HOMETAPYHGBH  
RRETHGUALUMULTIPLESCLEROSIS  
HGNIDNATSREDNURQZNSELIMSSIU  
XXDRPQYOGNINETSILPZCLUFPLEH  
TACTRUSTMOMJGRANPARENTSF  
DADSEIROTSRFEOLOVEZYTOD  
APMGLLCJAERPXXYNNUF  
CBTGBROTHERPETS  
SNHSISTERCS  
LEUHIWY  
LNH  
G

### WORDS TO FIND:

BROTHER DAD  
MOM SISTER  
PETS  
MULTIPLE SCLEROSIS  
LOVE HUGS

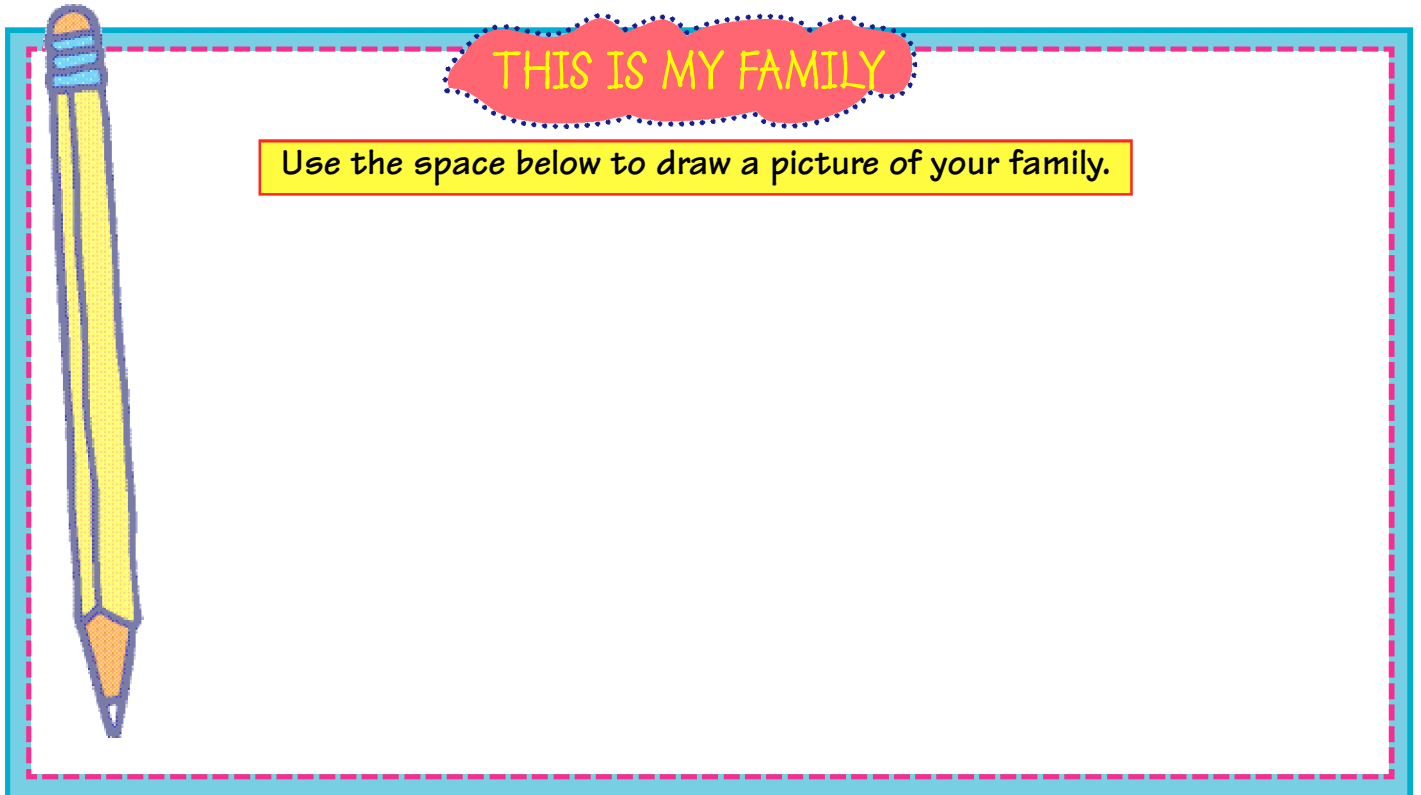




National  
Multiple Sclerosis  
Society



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

A large rectangular area for drawing. On the left side, there is a vertical illustration of a yellow pencil with a blue eraser and a sharpened lead tip. The drawing area is enclosed by a solid blue border and a dashed pink inner border. At the top center, the text 'THIS IS MY FAMILY' is written in yellow, all-caps, sans-serif font inside a red, cloud-like shape with a dotted border. Below this, a yellow rectangular box with a red border contains the text 'Use the space below to draw a picture of your family.' in black, italicized, sans-serif font.



# KEEP S'MYELIN

## PARENTS' PULL OUT

HOW TO ENJOY  
KEEP S'MYELIN  
WITH YOUR

KIDS



**T**his issue of Keep S'myelin is about families. You can use the articles and games to talk with your children about the ways MS has changed your family's routines or affected different members of the family.

**U**se the cartoon about Michael and his friends as an opportunity to talk about how family members and friends pitch in to help one another. Make sure your children know how proud you are of the "extras" they do for you and around the house.

**A**s you read Family Life and MS, encourage your

your children to share their feelings about MS and the changes it has made in their lives. Don't be afraid to share some of your feelings at the same time. See if you can work together to think up some new projects or activities to enjoy. These family activities will help remind all of you that even though MS may bring some changes into your lives, you can still have family fun.

**U**se Jeremy's story to talk about how it feels for your children to talk about the MS with their friends. You might even want to try a role play game to give your kids a chance to practice.

**T**he "What is MS?" article is a good introduction to talking about your own symptoms, especially those that your children can't easily see for themselves—like fatigue, stiffness, or vision problems.



**A**s you laugh together over the riddles and games, see if you can come up with other ways to share laughter. Encourage your kids to make up their own knock-knock jokes about MS—or anything else—and send them to us for future issues.

## PARENTS' CORNER

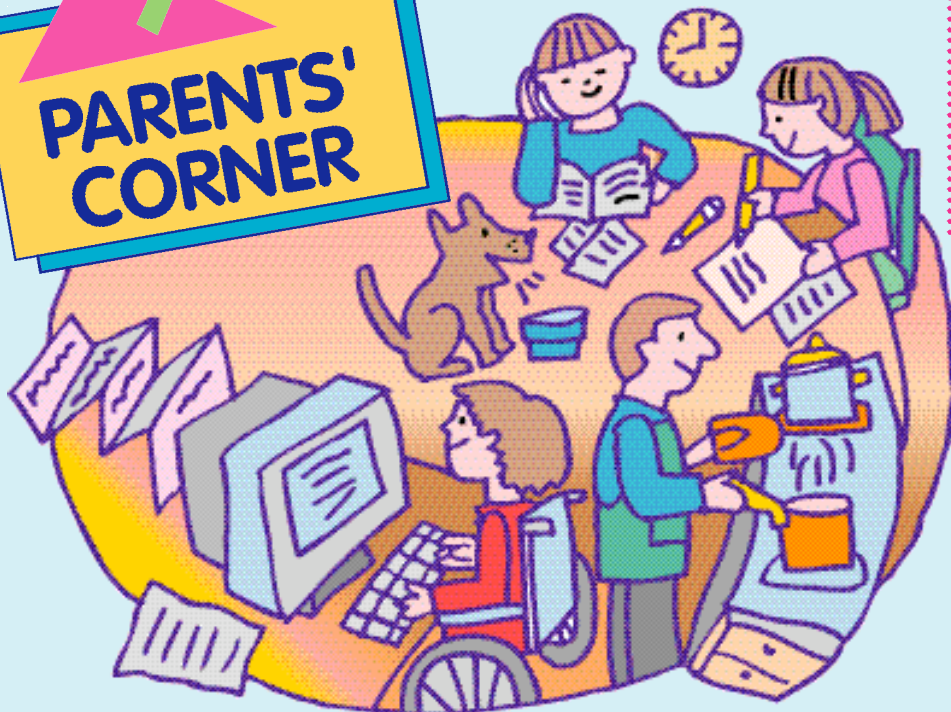
MS affects the whole family. Even young children are aware of changes in daily routines related to MS.

During exacerbations or if your MS progresses, you may need help from family, neighbors, or home health aides. The addition of these adults to the household can be confusing for your children, particularly if the newcomers begin to help with parenting activities. If they introduce different rules or routines, your children

may wonder who is in charge. To minimize conflict, clarify with your helpers what their role with the children is to be. Whatever you decide, it is

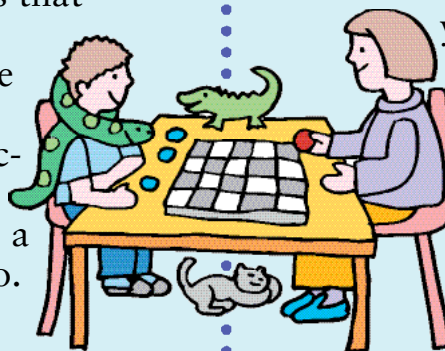
important for your children to know that you will always be the parent and that the other adults are there to help you.

At times it may feel as though you and your children have traded roles.



It is easy to make spending time together as a family a last priority in this busy world. Work days and school days are spent with families going in many different directions. When everyone finally gets home, one parent may be checking the e-mail while another is working on laundry. The kids are off doing homework or watching TV. Does this sound familiar?

Sometimes families have to schedule time together just like all the other things that are scheduled in our lives. But the payoffs are tremendous! Set the day and time. Choose things that everyone will enjoy—a drive to a special place for a picnic, a day at a museum, or a trip to the zoo. Or try just playing cards or a game around the kitchen table with a big bowl of popcorn and some hot chocolate!





## PARENTS' PULL OUT

During an exacerbation, or if you experience long-term changes in your symptoms, you may start to depend on them to help you or manage things around the house. This kind of role-reversal should, however, be avoided as much as possible.

Even though you may not be as active as other parents, it is important that you remain in the parent role. The structure and guidance you provide helps your children grow into their responsibilities gradually and gives them a sense of security.

The best strategy is to keep the household as normal as possible, while being realistic about the changes that MS may require. Children need to feel comfortable in their own home. The comfort level may drop significantly if you have a lot of medical equipment in the general living area, or if the children have no private space to see their friends. If major adjust-



ments or home modifications need to be made, it is a good idea to include your children in planning and implementing these changes.

MS is a part of your life – it doesn't help to ignore it or, on the other hand, to make it your main focus. A good way to achieve this realistic balance is to be honest with your children about what you need to do to manage your illness, get their ideas about how to do this, and show them that being their parent is one of the most important things that you do.

### 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.



Here's a fun activity to do as a family...

### The BEETLE Game



## PARENTS' PULL OUT

### The BEETLE Game

This fun game is for ages 5 and up. All you need is a pencil and paper for each player and one die.

Beetle is the original pencil-and-paper way to assemble your own bug. To start, each player rolls the die, and the one with the highest number goes first. He/she then rolls the die and tries to get a one. If a one is rolled, the player may draw the beetle's body (a large oval). If not, the player passes the die to the next player. Each kid gets one roll per turn.

To create his/her beetle, the player must roll each number from 1-5 in order. After all, players can't draw the eyes until the beetle has a head. The first player to put the whole beetle together is the winner!

Roll a 1= draw the body (a large oval).

Roll a 2= draw the head (a circle attached to the body).

Roll a 3= draw three legs on one side of the body.

Roll another 3= draw another 3 legs on the other side of the body.

Roll a 4= draw one antenna.

Roll another 4= draw the second antenna.

Roll a 5= draw one eye, another eye and a



### Finished Bug



© 2008

**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.

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.

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.

#### Editors

Rosalind Kalb, PhD  
Kimberly Koch, MPA

#### Design/Illustrations

Claude Martinot Design

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

#### Please give us feedback.

Send your questions or ideas to:

National MS Society  
KEEP S'MYELIN  
900 South Broadway  
Second Floor  
Denver CO 80209  
keepsmyelin@nmss.org