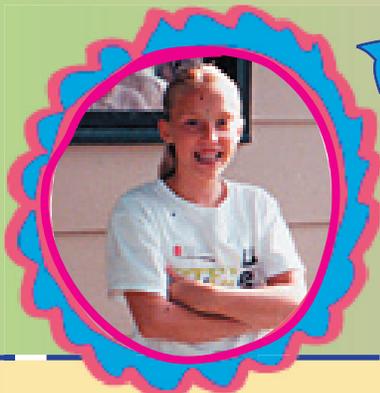




KEEP SMYELIH

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS



TAYLOR'S CARNIVAL

My name is Taylor. I am 12 years old and in the 7th grade at Pipestone Area Schools in Minnesota.

My Grandpa has had MS for many years, Last year I had a carnival for MS. It was a lot of fun, so we did it again this year.

We had many games including cake walk, plinko, fishing pond, skee ball, and bean bag foss. We also sold food and snacks. My family and friends helped me make this a huge success. We raised \$610.25 for the MS Society. We had a great time and hope to do it again next year.



My Grandpa is very special to me so I hope this will help in finding a cure.

Taylor

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."



**Keep S'myelin Readers:
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.



STACEY'S

STORY

My name is Stacey. I am 11 years old and my mom has MS. My mom can be grumpy, but then she stops and calms down. I sometimes get scared when my mom takes her shot. She sometimes gets reactions to her shots. Once my dad took my brother and me out on Halloween. When we got home, the ambulance was at our house. I got so scared I almost started to cry. I love her so much. So, when I grow up, I want to find a cure for MS. I want all people to be cured, especially my mom.

It is kind of hard having a mom with MS. When I am sick with a cold, I think that's bad. I just can't even imagine having and struggling to take shots, having reactions and other things. I just pray to God that one day some one will find a cure for my mom and all the other people in the world.

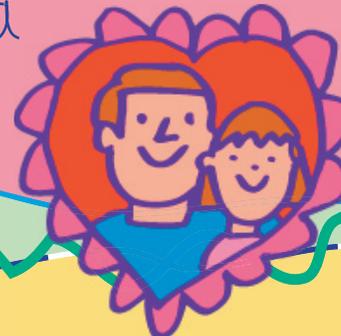
STACEY

LARA'S

STORY

My dad is the best! He may have multiple sclerosis, but it has not changed my life! He is my dad. I will always love him and he will always love me. Me and my sister and my mom help him a lot. He always helps me with my homework. I am 10 years old.

LARA





Joshua's MOM

"I am not a really great writer, but I read the stories in the Keep S'myelin mail that comes to our house and thought some kid might like my story. I know my mom was embarrassed that I picked her to write about, but after she read what I wrote, she told me it made her feel really good. I'm in the 7th grade."



My life has been changed forever. My mom was diagnosed with MS in 2000. We have been fighting this disease for about five years. It hasn't only been difficult for my mom, but my whole family—four kids and my dad as well.

One morning my mom woke up and had double vision. She didn't know what was wrong or how she got it. She went to the doctor to have some tests, and the tests showed that she positively had MS. Nobody is sure how long my mom has had MS, but they think that she has had it for a few years.

My mom took interferon injections to slow down her MS, but the side-effects to this injection were so bad that she ended up going to the hospital because of the medicine, not the disease.

My mom now has to stay cool so we sold our hot tub. She also switched from a full time job to a part time job in order to have less stress. She can't do a lot of physical activity, so we bought a bicycle she can ride with one of us so she can still enjoy our family bike rides. With these changes our family is still as strong as ever.

Sometimes having a disease can be a blessing. MS has made our family much closer than we were before. We are thankful for everything—even MS.

JOSHUA



MY MOM HAS MS

by Stephanie

My mom has MS. Her arm is numb. She has to squeeze a little ball to help the numbness and she has to take a shot every other day. She doesn't like taking the shot because it hurts a little, but she has to.

It is hard having a mom with MS. Maybe when they know why she has MS they could make it go away. Then, I would be happy because I could do more things with my mom. She got MS when she was thirty. Now she is forty-one years old. My mom has had MS more years than I've been born.

I wish my mom never got MS. I feel weird that my mom is the only one I know who has MS. I don't know anyone's mom or dad that has MS, but I wish I did. Then, I would feel a little bit better. I hope one day I'll meet another kid whose mom or dad has MS.

Stephanie

MY HERO GRANDMA

by Kelles



I have a special hero,
Her name is Grandzanne.
She teaches me lots of things,
most important that "I can!"

She's had lots of hard things in her life,
she's in a wheelchair, too.
But that has never stopped her,
from what she wants to do.

For years she was a teacher,
And now she writes a book.
She's always liked to fight MS,
No matter how much control it took.

Grandzanne is my role-model.
She's never down...instead,
She always looks on the bright side,
Eager to see what's ahead!

Kelles

(This poem won first prize in Kelles's school's literature contest.)





COUPONS OF LOVE

Here is a great gift idea for someone you love who has MS. Make a "coupon"! Here are some ideas for coupons you can give your mom or dad.

COUPON
GOOD FOR HUGS
AND KISSES,
ANYTIME

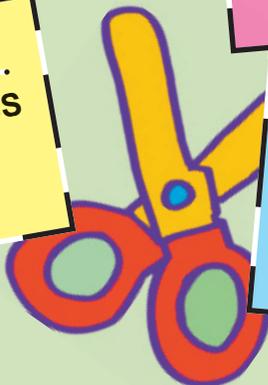
COUPON
GOOD FOR
AN AFTERNOON OF
CUDDLING AND
READING TOGETHER

COUPON
GOOD FOR
CLEANING OUT
THE GARAGE

COUPON
GOOD
FOR MAKING

COUPON
GOOD FOR

Your mom or dad will love this kind of present because it tells them you love them and want to help!



JOKES



Q: How much do pirates pay for their earrings?

A: Buccaneeri!

Q: You're a bus driver. At the first stop, 4 people get on. At the second stop, 8 people get on. At the third stop, 2 people get off and at the fourth stop, everyone gets off. The question is, what color are the bus driver's eyes?

A: The same as yours, you're the bus driver!



Q: What has a mouth but doesn't eat, a bank with no money, a bed but doesn't sleep, and waves but has no hands?

A: A river.

MICHAEL CRYSTAL AND BENJAMIN
S'IMYELIN KIDS

THERE'S ANOTHER KID AT AFTER-SCHOOL CARE WHOSE MOM HAS MS!

REALLY? I DIDN'T KNOW THERE WERE ANY OTHER MOMS IN OUR NEIGHBORHOOD WITH MS!

I GUESS YOU CAN'T ALWAYS TELL BY LOOKING. DID YOU TALK TO HER, CRYSTAL?

YEAH! IT WAS COOL. I DIDN'T HAVE TO EXPLAIN MS TO HER BECAUSE HER MOM HAS IT, TOO. IT FELT REALLY GOOD TO TALK TO HER!



PARENTS' PULL OUT

MAKING CONNECTIONS



A diagnosis of MS gets every family member's attention. Some members of the family cope by learning as much as they can about MS. Others may want information, but may also wish to connect with other families who are struggling with and adapting to MS in their everyday lives.

Whether or not to attend a program for people with MS can be a difficult choice for some. You may wonder, "What do I hope to gain from reaching out in this way?" "Will I meet others whose MS is like mine?" "What if my children or I meet someone who is more disabled?" Mobility constraints, energy depletion and transportation difficulties can also be obstacles to getting out. While no one program will meet every need, the benefits often outnumber the drawbacks. If nothing else, being with others helps us to remember that we are not alone. National



MS Society chapter programs offer a variety of ways to connect with others. You could attend a formal lecture on research, or an informal "Family Day."

You could participate in an exercise or aquatics class or attend a self-help support group, a care partners' support group or a kids' support group. One reason there are support programs for people with MS and for their family members is to encourage people to talk to each other. Just the exchange of stories—the connection with a fellow traveler—can be enormously healing. Sitting down with people who are experiencing the same pain and triumph can help you feel better. Attending National MS Society chapter programs can offer the opportunity to express feelings of frustration, anger, or sadness that others in your life may not understand in the same way. They can provide a forum to share challenges and lessons learned in living with MS.

How to Read this Issue with Your Child

At times, a disease like MS can make people feel very alone. Symptoms are so variable from one person to another that you may sometimes feel that no one else could possibly understand what you are experiencing. Like adults, children who have a parent with MS sometimes feel different and alone. Many, like Stephanie tells us in her story, want to know that they are not the only ones who have a parent with MS. Given the opportunity, they may want to connect with others who know what it's like. As you read this issue with your child, you can talk about what is different for each of these kids and their families, and what is the same. This is a good time to remind your child that MS is different for everyone who has it.

Ask your chapter about the programs it offers for children and give your child the opportunity to meet other kids and their parents.



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

ACTIVITIES TO DO TOGETHER

BIRTHDAY

SUPPLIES

- Colored pencils
- Scissors
- School glue
- Washable kid's paint
- Paint brushes
- Markers
- Recycled newspaper
- Recycled boxes
- Cardboard rolls from gift wrap
- White paper
- Ribbon
- Paper towels
- Cardboard
- Water containers



TOY CHAIR



WARNING: This chair does **NOT** support a child's weight. It is designed to display a stuffed animal, action figure, or doll.

1. Cut cardboard rolls into six pieces (4 legs, 2 back pieces) with scissors. Find a medium-size, square shallow box or lid (for the chair seat) and one or two strips of cardboard (for the chair back).
2. Paint all the pieces.
3. Assemble the chair. With glue, attach one tube (chair leg) in each corner of the box.
4. Turn over the chair bottom. Glue the remaining two tubes to the seat of the chair above the bottom back legs.
5. Glue the cardboard strip(s) to the two tubes that form the back of the chair.
6. Decorate the chair. On construction paper, use your imagination and colored pencils, markers, or crayons to draw pictures, designs, streamers, and any other suitable decorations.
7. Cut out pieces and glue your designs to the chair. Glue garlands of ribbon to the seat. Display your dolls, superheroes, or other lightweight items in the chair.



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.

MEET CINDY



NOTE TO PARENTS

Here is a letter written by someone with MS who was a teacher and principal. Reading this with your child(ren) can help them realize that there may be other families in their community who are living with MS, and they are not alone.

Hi, my name is Mrs. Shaffer, but you can call me Cindy. I have MS, just like an important person in your life. I used to be a teacher and then I became an elementary school principal and I did that job for 25 years. When I was at work, my teachers knew about the MS, but the students did not. MS affects people in different ways, and my most difficult symptom is fatigue. You know that teachers and principals are very busy. They hardly ever sit down and always seem to be in a hurry. I wonder if any of the workers at your school has MS? I recently retired from my job because I didn't have the energy to make it through each day. I knew that I had to do a good job for the students, teachers, and parents who were counting on me, too but my family was counting on me too. Each day I worked many hours at school, and then went to

bed very early. My family helped with chores around the home so that we could have fun on the weekends. Since I retired from my job, I volunteer to help other people with MS. I teach people about the disease, talk with others who have it, and work in the local National MS Society office. I even volunteer in a local preschool. I am 50 years old and I have a husband and a daughter who is an actress. I have 5 cats and 3 dogs. If you saw me on the street you would not know I have MS, but I do. MS can be very frustrating, but it does not mean I have to stop doing the things I enjoy. I go to the theatre, I garden, I take vacations, and I work out at the gym. I have MS, but that is not who I am, it is just another part of my life.

CINDY



ISSUE #21
Keep
S'myelin
CONNECTING
WITH OTHERS

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.

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 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.

Editors

Debra Frankel, MS, OTR
Rosalind Kalb, PhD
Kimberly Koch, MPA

Advisors

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

Design/Illustrations

Claude Martinot Design

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