Parents with MS and their kids seem to have many of the same concerns and experiences regardless of where they live in the world. This issue of Keep S’myelin takes you on a trip around the world to learn more about MS. We talk to a child in Italy whose mom has MS and to a psychologist from the MS Society in Australia who works with families. We learn how to say MS in different languages! And there’s a lot more. We hope you enjoy learning about MS around the world!

**FACT:**

An estimated 2,500,000 people in the world have MS.

**FACT:**

MS is more common in countries that are far away from the equator.

**FACT:**

There are over 38 MS Societies all around the world. Each MS Society helps people with MS in their country. There are MS Societies in the United States, Australia, Brazil, Canada, Italy, Ireland, France, Japan, Qatar and Zimbabwe.
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.

Surprisingly 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.”

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
BROADWAY STATION
900 South Broadway
Suite 200
Denver CO 80209
or e-mail to
keepsmyelin@nmss.org
Sara is 11 years old and lives in Genoa, Italy. She likes reading, fencing, and cooking. Her favorite subjects at school are French, English, music, and art. She has three birds named Arancia, (which is the Italian word for “orange”), Limone (which means “lemon”), and Brioche (which is a type of roll). Sara wants to be a chef when she grows up. (Thanks to Michele Uccelli from the MS Society in Italy for conducting this interview and translating Sara’s answers.)

**Keep S’myelin:** How did you learn that your mom had MS?

Sara: My mom and dad told me. My dad showed me my mom’s MRI* with the white spots and explained that the spots on Mom’s brain made it hard for her to do certain things.

(*An MRI is like a special x-ray. It helps a doctor know if someone has MS.)

**Keep S’myelin:** Do you remember how you felt when you found out?

Sara: I was only six at the time and I didn’t really understand what it meant.

**Keep S’myelin:** How do you learn about MS now if you have a question?

Sara: I ask my mom or I ask the physiotherapist from the MS Society when she comes to our house.

**Keep S’myelin:** How has MS affected your family?

Sara: MS has caused some worry for our family. My grandma and aunts and uncles worry about how I’m doing. I think I’ve grown up faster.

**Keep S’myelin:** Have you made any changes to your home because of MS?

Sara: We put grab bars in the bathroom for my mom. We also lowered the buzzer that opens the door down stairs in our apartment building, so mom can open the door when she’s sitting on the couch. Also, we rearranged the bedroom so her side of the bed is closer to the bathroom. Mom has a wheelchair to use outside and a walker to use inside. We have a special parking space outside our building.

**Keep S’myelin:** How do you help your mom?

Sara: I wash the dishes, help her get to the bathroom, and I bring her things like her slippers. I also push the wheelchair along behind her when she walks in the house.

**Keep S’myelin:** Any message to children in the United States who have a parent with MS?

Sara: Accept your mom or dad no matter what and be happy because MS is not such a big problem. Your mom or dad isn’t an extraterrestrial from outer space, but just your mom or dad, same as before!

**Keep S’myelin:** How do you say “multiple sclerosis” in Italian?

Sara: Sclerosi multipla.
Make a Papier-Mâché Globe

Make a globe out of papier-mâché using strips of old newspaper and paste made from flour and water.

Supplies:
- Large balloon
- Flour
- Water
- Newspaper
- Poster or tempera paint

1. Make the paste by mixing 1 part flour with 2 parts water.
2. Tear newspaper strips about 1 inch wide and 3 inches long.
3. Blow up a balloon and tie it.
4. Dip the strips of newspaper in the paste and wrap the balloon as smoothly as possible with one layer of papier-mâché strips.
5. Then wrap again with three more layers. Next, use the papier-mâché to make mountains and valleys.
6. Let the balloon dry for at least 24 hours. Using poster or tempera paints, paint the continents and the oceans!
**COUNTRIES AROUND THE WORLD**

**WORD SEARCH**

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UNITED STATES
L W T H N E N G L A N D
A E A A L N F R A N C E
D Y L I O M P T O M U X
Y I Y L L A F R B A D T
A S P A F R L A B E I O
O R P N R K P E R U S U
I A D D X C A N A D A S
M E X I C O Z O Z P N M
E L A S P A I N I T S B
I R E L A N D O L D B D
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Clue: All country names are horizontal or vertical (no diagonals!)

**JOKES**

- How do you fix a broken pizza?
  - With tomato paste!
- Why did the cookie go to the hospital?
  - Feeling crummy.
- What kind of fruit do you feed a scarecrow?
  - Strawberries.
1. Hi, Ben. Have you met my friend Miguel? He lives in Spain. His mom has MS and they are visiting us.

2. ¡Hola! How do you say multiple sclerosis in Spanish?

3. Sounds almost the same as MS in English, only the words are switched around!

4. ¡Ten cuidado! Be careful!

Multiple sclerosis = esclerosis múltiple

Be careful! = ¡Ten cuidado!
Australia is about one-third the size of the United States and has a much smaller population. There are about 20,000 people with MS in Australia (compared to about 400,000 in America). Like the MS Society in the United States, the MS Society in Australia offers children’s programs for kids who have a parent with MS.

Most of the children’s programs happen during school holidays. Artists, actors, storytellers, and game leaders join the MS Society staff and help lead the programs. They help the kids mix and mingle and have a good time. Kids talk to each other about what it is like to have a parent with MS. There is a chance to have questions answered. Kids can ask frightening questions about MS that they may be afraid to ask their parents. These are the same questions that worry kids all over the world: “Will my mum or my dad die from MS?” “Will I get MS?” “Did I cause my parent’s MS?”

Another program for kids and their families is Family Camp. At the campsite, grown-ups and kids play lots of “getting to know you” games so that everyone can link up with someone “in the same boat.” There are plenty of activities for everybody: canoeing, sailing, horseback riding, team games, discussions, hikes, and quiet games.

Many lasting friendships have started at Family Camp. Often, kids keep in touch with their new friends by phone or e-mail. Sometimes, there are camp reunions. Family Camp helps kids and their families learn a lot about MS and feel less alone.

Thanks to Lindsay Vowels, PhD with the MS Society of Victoria, Australia.
Contact your National MS Society chapter at 1-800-344-4867.
In this issue of Keep S’myelin, your children will learn about the larger world of MS. Since families can sometimes feel very alone in their efforts to cope with the impact of MS, it may come as a surprise to learn that parents and children around the world are sharing this experience—and that MS Societies like ours are working to support their efforts. Talking about how families in other countries manage MS, and visiting the web site of the Multiple Sclerosis International Federation, will help you all to feel part of a large, proactive team.

As you and your children read about families in other countries, ask them how they think these other kids might be feeling, what questions they might have, what their lives might be like. This will give all of you the opportunity to talk about the shared experiences of families everywhere, as well as some of the important differences.

If you have a globe or atlas in your home, be sure to look at all the places mentioned in this issue. If you don’t have either of these, you can mark the places on your papier-mâché globe! While painting in the continents and oceans, you and your kids can practice saying, “la sclérose en plaques,” or letting, “il sistema nervoso centrale,” roll off your tongues.

If your family is planning a vacation, take the opportunity to get your children involved in the planning. Visit the travel web sites or call and ask for brochures about accessible travel opportunities. Engage your kids in thinking about ways to make the trip easy, fun, and accessible for every member of the family.
Barrier-Free Travel: A Nuts And Bolts Guide For Wheelers And Slow Walkers by Candy Harrington
This book is a well-researched resource that contains detailed information about the logistics of planning accessible travel by plane, train, bus and ship. It contains resources, travel tips and updated information about accessible travel options. Available through Demos Medical Publishing www.demosmedpub.com

Emerging Horizons: Accessible Travel News www.emerginghorizons.com
Emerging Horizons is a consumer oriented magazine about accessible travel. Emerging Horizons’ primary focus is travel for people with mobility disabilities.

Handicapped Travel Club, Inc. www.handicappedtravelclub.com
The Handicapped Travel Club, Inc. (HTC) was formed in 1973 to encourage traveling for people with a wide range of disabilities. The HTC encourages people with disabilities and their families to travel, to meet and to share information on making recreational vehicles accessible for the disabled. Note: There is a membership fee.

Society for Accessible Travel and Hospitality (SATH) 212-447-7284 www.sath.org
SATH has been representing the interests of disabled travelers for 25 years. They have gathered a great deal of information about access in many worldwide locations.

Access-Able Travel Source Tel: 303-232-2979 www.access-able.com
Access-Able Travel Source is dedicated to aiding travelers with disabilities and the mature traveler. The website contains information not only on accessible accommodations, but everything to make a trip fun and exciting.

As of the printing of this newsletter, all web addresses and phone numbers were accurate. If you discover an inaccuracy, we encourage you to perform an internet search.
MULTIPLE SCLEROSIS INTERNATIONAL FEDERATION
Mission: Making worldwide connections to end multiple sclerosis and its effects.

Tel: 020 7734 9120
www.msif.org

The Federation seeks to work in worldwide partnership with member MS societies and the international research community to eliminate multiple sclerosis and its consequences, and to speak out globally on behalf of those affected by multiple sclerosis.

Go to the MSIF’s website for information on the worldwide research effort, translations of information about MS in 20 languages, contact information for member MS societies, information on all aspects of MS, personal profiles and more.

• TALKING WITH YOUR CHILDREN ABOUT MS
How to Talk about MS with Your Children is a booklet that offers practical advice to parents to help them communicate more effectively with their children about MS.

• MYELIN IS GETTING ON MY NERVES is an illustrated activity book designed for children aged 6-12 and their families.

Requests for these booklets can be made by calling the MS Society of Canada at 1-800-268-7582 or by e-mail at: info@mssociety.ca.

PLAINTALK: A Booklet about MS for Families discusses some of the more difficult physical and emotional problems many families face. By Sarah Minden, MD, and Debra Frankel, MS, OTR.

SOMEONE YOU KNOW HAS MS: A Book for Families, for children ages 5-12. A story about Michael and his family explains MS and explores children’s fears and concerns. Adapted by Martha King from original material by Cyrisse Jaffee, Debra Frankel, Barbara LaRoche, and Patricia Dick.

Requests for these publications can be made by calling the National MS Society at 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.

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