



# Keep S'myelin

A NEWSLETTER FOR KIDS ABOUT MULTIPLE SCLEROSIS



## MS AROUND THE WORLD



In this issue we travel around the world... interviewing MS researchers in Cyprus and Switzerland, talking with Matthew from Canada, learning how to say hello in Japanese, and much more!

Over one million people in the world have MS and scientists in the United States and in many other countries are working together to find the answers to MS.



We hope that this issue of Keep S'myelin will get you thinking about places beyond your neighborhood. Maybe it will make you think about traveling to new countries and learning about other people. Also, we hope this issue will help you know that you are not alone... families across the globe are thinking and learning about MS, just like you!



# 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](mailto:keepsmyelin@nmss.org).

# STUDING MS IN CYPRUS



**Cyprus** is a small island in the Mediterranean Sea. Even though there are not very many people living in Cyprus, a lot of people there have MS. The island has a Neurology Center that provides treatment for people with MS. Keep S'myelin talked to Dr. Kleopas who lives in Cyprus and does research on MS at the Neurology Center. Here's what he said.



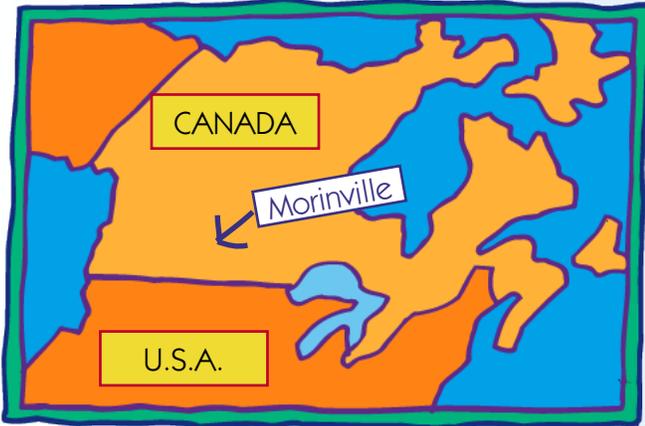
For one of our research studies, we are working with scientists from the United States to discover what causes damage to the myelin in the brains of people with MS. We are looking at the special molecules that allow the cells in the brain to "talk" to each other. The research has already shown that myelin becomes damaged when cells are not working together the way they are supposed to. We are also examining the special cells that make myelin.

We will use the new information about how myelin damage occurs to develop new MS treatments.

Here on Cyprus, we are working on other research projects too! We are studying how viruses might cause MS. We are doing experiments to see if a treatment with electromagnets can help people feel less stiff and walk more easily. And, we are looking at a special diet to see if certain types of foods can make MS better. Wouldn't it be fun to visit Cyprus and talk to us about our work?

# INTERVIEW WITH

# MATTHEW



Matthew is 9 years old and in the 4th grade in Morinville, Alberta, CANADA. He lives with his two younger brothers (twins!), his mom and dad, and his dog, Kopper. He is an 'A' student in math and he and his dad like to read Harry Potter together. Matthew's mom has had MS since he was 5 years old. This past summer, Matthew attended MS Kids Camp, a program offered by the Edmonton Chapter of the MS Society of Canada.

**KS:** What was MS Kids Camp like?

**Matthew:** It was fun. The three things I liked the best were mini-golf, bowling, and writing a poem about my mom and her MS. (Matthew's poem appears on this page.)

**KS:** Did all the kids at MS Kids Camp have a mom or dad with MS?

**Matthew:** Yes. We learned about MS together and got to do a lot of fun things.

**KS:** What advice do you have for a kid who has just learned that his or her mom has MS?

**Matthew:** Go to Kids Camp\* and learn about MS! Doctors are working on a cure, so you have to wait and be patient until they find it.

**KS:** What is it like having a mom with MS?

**Matthew:** That is what my poem is about. Here it is:

## How M.S. Affects My Mom

The first thing that gave my Mom a fright,  
 Was a problem with her good eyesight.  
 Usually things were nice and bright,  
 But now one eye was dark as night.  
 After a while her sight came back,  
 But the cause they said was an MS attack.  
 As time went on there was numbness and pain,  
 And now when she walks, she uses a cane.  
 The biggest thing I've noticed about my Mom,  
 Is how very tired she has become.  
 I hope one day we find a cure,  
 Then things can go back to the way they were!

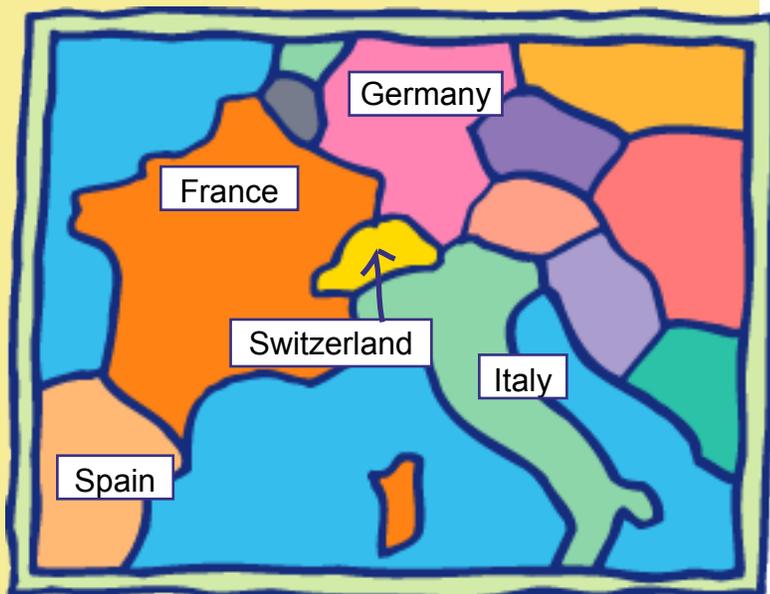
Matthew

\* Some MS Society Chapters have Kids Camp just like the one Matthew went to or other programs for children. Call 1-800-FIGHT-MS to contact your chapter.

# MS RESEARCH IN

# SWITZERLAND

Switzerland is a very small country in the middle of Europe. It is full of mountains, called the Alps. The Swiss are known for their excellent chocolate (yum!), cheeses, and very accurate watches. There are about 10,000 people with MS who live in Switzerland. Even though Switzerland is very small, its universities are very good and so are its doctors and scientists. Keep S'myelin talked to scientist, Becher Burkhard at the brand new MS Research Center at the University of Zurich. Researchers there are working to understand why some people develop MS and to find ways to help them. This is what Dr. Burkhard told us.



**T**he immune system is a large army of cells that protects people against 'invaders' like viruses and bacteria. We believe that the immune system in people with MS gets confused. It seems to think

that something in the brain is like an invader and so it starts to attack it.

**A**lthough the brain of a person with MS tries hard to defend itself, the immune system has much better weapons, so the myelin in the brain becomes damaged.

**W**hy does the immune system attack the brain? This is one of the most important questions we try to answer. Perhaps we can teach the immune system to leave the brain alone

and go after the real invaders instead—sort of like giving the "immune army" new instructions.

**W**e work with many doctors and scientists from all over the world. When you have a big task, like cleaning up the mess in your room, it always helps when your mom or dad or a friend helps you to get that job done. For us researchers it's the same thing. When we all work together, our job gets much easier.

# SAY HELLO!

**Q** If you wanted to say hello to everybody in the world, how many people would that be? And how many languages would you have to learn?

**A** You would have to say hello to almost 6,000,000,000 people and learn at least 2,796 languages! Here are some examples:



Pronunciation:  
NAH-zdar ihmeh-noo-EE seh



Pronunciation: koh-NEE-cheewah  
Wah-TAHK-sheewah (your name)-DEHSS-ew



Pronunciation:  
ZzDRAST-vet-yah Men-YAH zoh-VOOT



Pronunciation:  
goo dahg meet nahmn air

Visit this website to learn more!: <http://www.ipl.org/youth/hello/>

MICHAEL CRYSTAL AND BENJAMIN  
**S'MYELIN KIDS**





PARENTS' PULL OUT

# Reading Keep S'myelin with Your Kids

This issue of Keep S'myelin exposes readers to the international MS research effort and to places and people around the world who are thinking and learning about MS. Here are some tips about reading this issue with your kids:

◆ Reading about MS research in **Cyprus** and **Switzerland** can reassure children that doctors in the United States and around the world are working hard to find treatments for MS.

◆ Visit the **web sites** listed in the Parent Section. You and your children can broaden your horizons by learning together about customs, food and history in countries across the globe. Try saying "Hello" to each other in Russian and Swedish!



◆ Prepare some of the **international recipes** together with your kids. While some of the tasks are fine for kids to do, be sure an adult does

any cutting, frying and cooking over a flame. Talk about a pretend trip you might take around the world... what sites would you visit?, what would you eat?, what language would you speak?, what gifts might you purchase?

◆ As you read the interview with **Matthew**, encourage your child to write a poem or story about MS. Look into programs at your local chapter for families and/or children. Your chapter might offer a **Kids Camp** program like the one Matthew attended. (Call 1-800-FIGHT-MS) to be connected to your chapter.

# INTERNATIONAL RECIPES

## AVOCADO AND FRUIT SALAD

from Israel

- ◆ 1 grapefruit
- ◆ 2 tangerines
- ◆ 3 pineapple slices
- ◆ 1 avocado
- ◆ 1/4 lb. grapes
- ◆ vinaigrette salad dressing
- ◆ curry powder
- ◆ sugar to taste



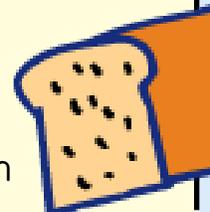
1. Peel and separate the grapefruit and tangerines. Cut the pineapple slices in half. Carefully peel the avocado and slice into strips.
2. Combine the fruit in a bowl. Toss with the dressing mixed with curry powder and sugar to taste.
3. Top with avocado slices and chill for at least one hour.



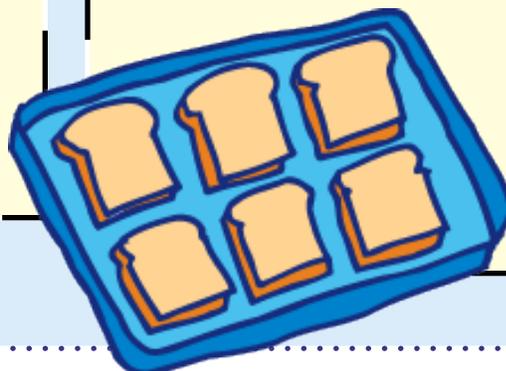
## BAKED FRENCH TOAST

from

- ◆ 1 loaf French bread, cut diagonally in 1 inch slices
- ◆ 8 eggs
- ◆ 2 cups milk
- ◆ 1 1/2 cups half-and-half cream
- ◆ 2 teaspoons vanilla extract
- ◆ 1/4 teaspoon ground cinnamon
- ◆ 3/4 cup butter
- ◆ 1 1/3 cups brown sugar
- ◆ 3 tablespoons light corn syrup



1. Butter a 9x13 inch baking dish. Arrange the slices of bread in the bottom. In a large bowl, beat together eggs, milk, cream, vanilla and cinnamon. Pour over bread slices, cover, and refrigerate overnight.
2. The next morning, preheat oven to 350 degrees F. In a small saucepan, combine butter, brown sugar and corn syrup; heat until bubbling. *(Be sure a parent closely supervises this step.)* Pour over bread and egg mixture.
3. Bake in preheated oven, uncovered, for 40 minutes.



# INTERNATIONAL RECIPES

France

## BANANA FRITTERS

from Mexico

- ◆ 1/2 cup milk
- ◆ 2 bananas, mashed
- ◆ 1/2 teaspoon salt
- ◆ 3 teaspoons baking powder
- ◆ 2 eggs, beaten
- ◆ 1 tablespoon margarine, melted
- ◆ 1 quart vegetable oil for frying
- ◆ 1/2 cup confectioners' sugar



**1.** In a mixing bowl, combine the milk and bananas. Sift in the salt and baking powder. Thoroughly mix in the eggs and margarine.

**2.** Heat the oil in a large skillet to 365 degrees F

**3.** Carefully place spoonfuls of the mixture into the hot oil and fry until brown. *(Be sure a parent closely supervises this step.)* Flip the fritter and continue to brown.

Remove fritters from the oil and drain on paper towels.

Dust the fritters with confectioners' sugar and serve while warm.



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.

# WEBSITES

That Will Broaden Your Horizons

Here are some websites to visit with your children to expose them to the global community.

**GLOBAL VILLAGE** - Take a peek at places and people around the globe without even leaving your home. Catch up on current affairs or find out what kids living in another country are thinking and doing! These links are wonderful tools to learn about others.  
[www.kids.gov/k\\_village.htm](http://www.kids.gov/k_village.htm)

**PASSPORT KIDS** - Online club that connects kids ages 6-12 around the globe. This site was developed by Sesame Workshop whose mission is creating media to educate children and their families. Passport Kids provides a safe environment where children can express their opinions and compare their experiences as they explore the world.  
[www.sesameworkshop.org/passport/](http://www.sesameworkshop.org/passport/)

**UNITED NATIONS CYBERSCHOOLBUS** - This site for students has access to country profiles, an introduction to the history and work of the United Nations, and some fun quizzes (such as the one on national flags) and the Urban Fact Game, an on-line quiz about cities and their populations. [www.un.org/Pubs/CyberSchoolBus/index.html](http://www.un.org/Pubs/CyberSchoolBus/index.html)

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



**ISSUE #20**  
Keep  
S'myelin  
**MS AROUND  
THE WORLD**

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.*