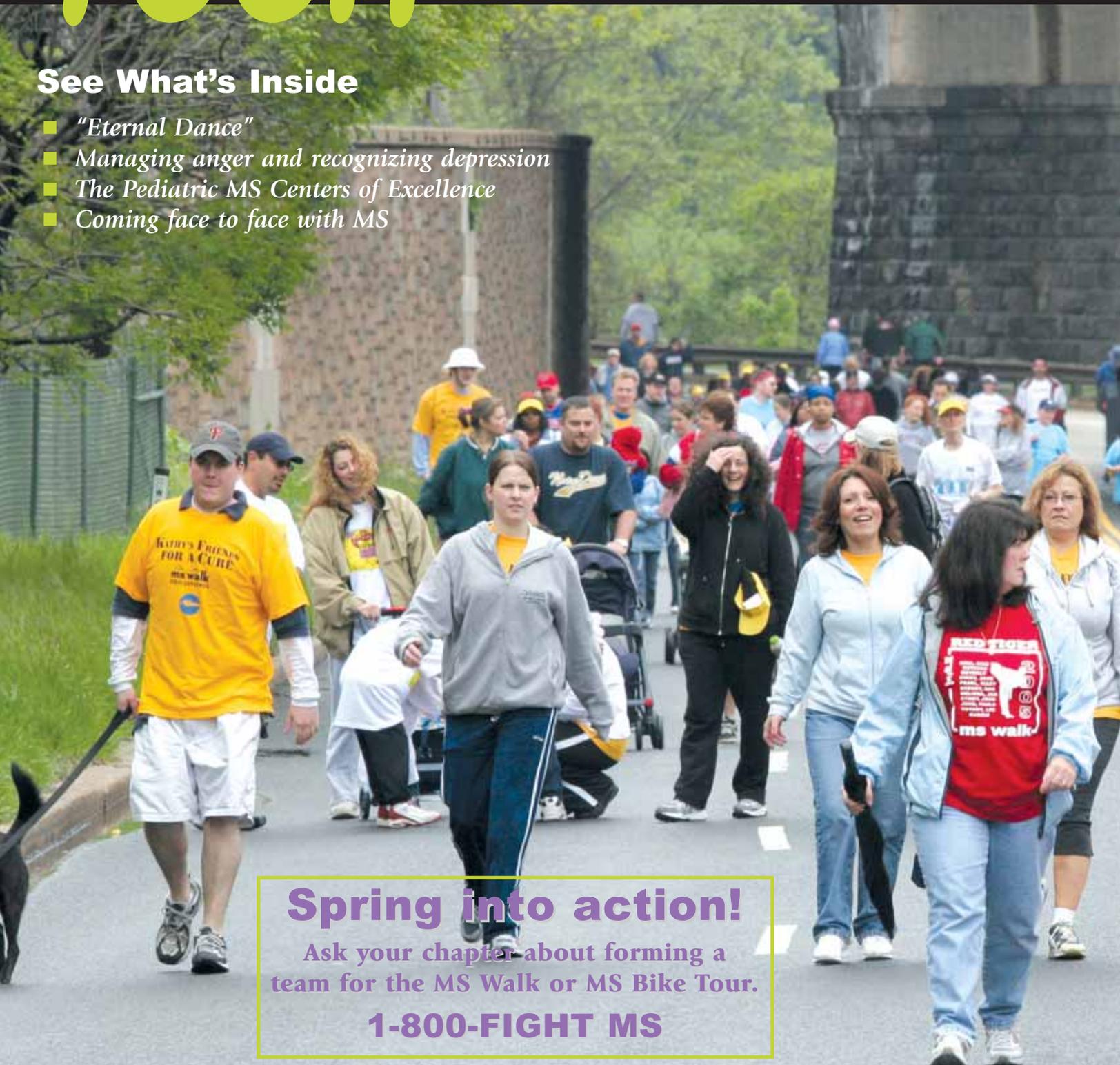


teen *inside* MS

See What's Inside

- "Eternal Dance"
- Managing anger and recognizing depression
- The Pediatric MS Centers of Excellence
- Coming face to face with MS



Spring into action!

Ask your chapter about forming a team for the MS Walk or MS Bike Tour.

1-800-FIGHT MS

(Cover photograph—MS Walk 2005; courtesy of the Greater Delaware Valley Chapter.)



Eternal Dance

*D*elicate steps that sweep her across the stage, feet whispering of a timeless presence that captivates the audience; a blossom of radiance to bestow a light-illuminating smile. They wept at her performances, because they knew that they would never surpass her. I wept as she danced because only I knew her secret. She is all that is grace, beauty eternal. She is my mother, and she is dying.

The box of photographs spill out onto the floor, scattering lost images like the scattering of lives somehow falling from the same origin. Glancing down I see my own image starring up from the picture lying on the top of the pile. Funny how the things we never want to remember jump straight into view at the most inconvenient times.

I vaguely recognize the little girl that beams up at me. Her red tutu floats about her waist with perfectly poised hands, eyes radiate passion with the painted smile of a porcelain doll; the perfect little ballerina. I close my eyes for a brief moment and I see myself glide across the stage, easily the most captivating, easily my mother's daughter. The music from that year's performance haunts my memory as it blocks out all other sounds.



 *I've got a present for my mommy, can you guess what it is ... no it isn't a guessing game and it's not a TV quiz ... I bought this present by myself, I saved up for it too ... and here it is all beautifully wrapped, in ribbons of pink and blue ...* 

The bittersweet memory fades as I remind myself that I don't need dance anymore. If she can't dance, neither should I. I hear the squeak of her electric wheelchair, so different from her past whispering steps. Such an independent spirit imprisoned by such a relentless and dependent disease. That's what multiple sclerosis is. Dependency and forced maturity. Another reason I'm so strong-willed, stubborn. You have to be strong-willed when someone else's life depends on it. I have to keep her spirits dancing; I will not let her fall.

The call comes in the early evening. No, I think with slow confusion, she's not here because she's performing tonight. She is dancing for them again; they don't care about the others, because they've all gone to watch her. But that is impossible. She hadn't been able to dance for years.

Deliriously, I tiptoe around the hospital, eventually finding my way to her room. The cold metal that surrounds her, a stark contrast to her warm spirit. The room dims in comparison to her light.

I gently take her hand in mine, and as weak as she is, I am weaker still. Her fading beauty twirls around the room, more than ready to dance again. She tells me that everything is fine, that she will always love her little ballerina. I bury my head into her chest and softly sing ...

 *I've got a present for my mommy,
can you guess what it is ...*

One last breath, one last tear. She is all that is grace, beauty eternal. She is dancing among angels now; angels, just like her. 



MANAGING ANGER



Anger with MS is part of living with MS. Anger is a normal adaptive human emotion, a signal that something needs to be changed.

According to Dr. Randolph B. Schiffer, professor of Neuropsychiatry and Behavioral Science at Texas Tech University, people deal with two kinds of anger when it comes to MS. There is “existential anger”—about the injustice of it all. There is “instrumental anger”—the anger that comes from everyday frustrations caused by MS.

He believes that the two kinds of anger are fundamentally linked. We must all come to terms with the injustice and then learn to balance out the frustrations in daily life. Anger can fuel positive problem solving.

According to Peggy Crawford, PhD, a clinical psychologist with the Cleveland Clinic’s Mellen Center for Multiple Sclerosis, “Anger often comes in waves.” Again and again as new problems appear or old problems come back in new ways.

Anger can become a rationale for inappropriate behavior.

Anger is a normal feeling

Learning that anger is normal helps pave the way for you to seek help. Why would you want to take this step? Very simply, anger can rob you of the energy you need to live your life. Anger can become a rationale for inappropriate behavior. Anger can be a cover for hidden feelings like fear and a sense of helplessness.

How angry are you, how often, and when?

These basic questions—how angry are you, how often, and when?—can lead to identifying ways to deal with your stress. Men and women tend to express anger differently. Men are more likely to show their anger. They become assertive, even bullying. Women often resort to passive-aggressive behavior. They retreat into silence—and resentment. Both behaviors are made of the same basic stuff. The reason to explore the whys and whens of your anger is to come up with solutions you can use to manage it in more healthy ways. Understanding what triggers your anger can help you dodge many explosions.

What are some solutions?

When you feel the heat rising:

- Do something physical as a release: Hit a pillow, rip up paper, let out a scream, go for a walk, get on a bike, or use any other piece of exercise equipment.
- Let music calm you: dance or sing your favorite songs as loudly as you can.
- Use the soothing power of water: take a shower, relax in a bathtub, swim.
- Count to 10, then shift to deep breathing or any relaxation technique.
- Escape into a book or movie and lose yourself in someone else's life.
- Pray or meditate—these are powerful tools for managing anger.

To help keep your anger under control:

- Practice relaxation techniques: breathwork, yoga, tai chi, guided imagery, meditation.
- Exercise regularly.
- Keep an Anger Diary or journal.
- Talk to someone close to you—friend, family member, or peer.
- Find out about available support groups. Just call the Society. A network of MS friends can make a difference.
- Ask for professional help from a qualified counselor.
- Engage in activities that include other people— isolation can fuel rage.
- Be kind to yourself.
- Volunteer.
- Develop creative outlets—paint, draw, write, take photographs.
- Use laughter to turn the anger away. Watch a comedy on DVD or TV.

Adapted from an original InsideMS article by Joyce Render Cohen and Gayle R. Dinerstein.

(We welcome your feedback—editor@nmss.org)

DEPRESSION



Someone once said depression is MS's evil buddy. And there's truth to this. First, many MS researchers think there may be a biological connection between MS and depression. Second, changes in family life because of MS easily cause conflicting emotions and turmoil that can set the stage for depression.

Whether you or someone in your family is the one with MS, there are some basics you should know.

True depression is not a fleeting emotion. It is a persistent disturbance of mood with marked symptoms (see box). The symptoms of a major depressive episode last at least two weeks. During that time, the person has five or more of these symptoms on a daily, almost round-the-clock basis. Clinical depression is not the normal, transient "blues" that everyone experiences in response to sad or distressing events. The symptoms not only persist, they impair daily functioning. One (or both) of the first two symptoms is always present in a major depressive episode.

How do you know if it's sadness, grief, or major depression?

Grief and sadness lift a little when something pleasant happens. Depression stays in place. Things that would normally give a person pleasure have no effect. Recognizing depression in someone with MS is not always easy because some of the symptoms are common to MS as well, such as fatigue or problems with concentration and memory. Being aware

- Feeling sad or empty or being irritable or tearful most of the day.
- Loss of interest or pleasure in most activities.
- Significant weight loss or gain or a decrease or increase in appetite.
- Sleeping too much or inability to sleep.
- Physical restlessness or slowed movement observed by others.
- Ongoing fatigue or loss of energy.
- Feeling personally worthless or guilty without appropriate cause.
- Diminished ability to concentrate or make decisions.
- Recurrent thoughts of death or suicide, or planning suicide.

(Adapted from the Diagnostic and Statistical Manual of Mental Disorders, American Psychiatric Association)

that depression is neither “natural under the circumstances” nor a sign of weakness may help in identifying it.

Ask for help

If depression is the problem, specialists agree—don’t wait; reach out. Ask other family members for help. If you don’t have siblings or another parent at home, talk to a school guidance counselor or call your Society chapter. Call 1-800-FIGHT-MS (1-800-344-4867). Your call will go straight to the nearest office. A medical check-up, counseling, and possibly medication will be needed to control a true clinical depression.

If you or your parent feel overwhelmed—but don’t have persistent depressive symptoms—you still need to reach out if things are tough at home. Talk with other family members. Ask relatives, even if they live out of town.

Getting Support

Many teenagers say that the best help they ever found was through support groups with other teens whose parents have MS. Some Society chapters have teen support groups and some have peer counselors. If there’s no MS teen support group near you, a school counselor may know about a support group for teens whose parents have some other type of chronic disease or disability. While their experiences may not match yours identically, you’ll have many common issues to share.

Counseling

If things are really tough at home, your chapter will have a list of counselors or social workers in your area who have experience with MS. Be aware that a fee is usually involved for professional counseling. If money is tight, or if you don’t want to enlist your parent in getting help, say so when you talk to the chapter. 

Adapted from Depression and Multiple Sclerosis and When a Parent Has MS: A Teenager’s Guide.

(We welcome your feedback—editor@nmss.org)

**A message from Dr.
Lauren Krupp,
director of the
National Pediatric
MS Center* at Stony
Brook, New York**



“MS is typically diagnosed in adults, but children as young as two have developed it. In our center, 95% of the children and teens with MS do not have a parent with MS. It is critically important for adults with MS not to think that their children are at risk.

“It is just as vital for young adults who have a parent with MS not to think that they are at risk. Genetics plays a very small role in making a person susceptible to MS.”

* Pediatric MS Center of Excellence

Promise: 2010

To encourage research into highly promising areas and to improve MS patient care, the National MS Society has launched **Promise: 2010 Campaign**. The campaign will raise \$30 million to fund areas that hold great potential in the fight against MS, but which have so far been under-explored.

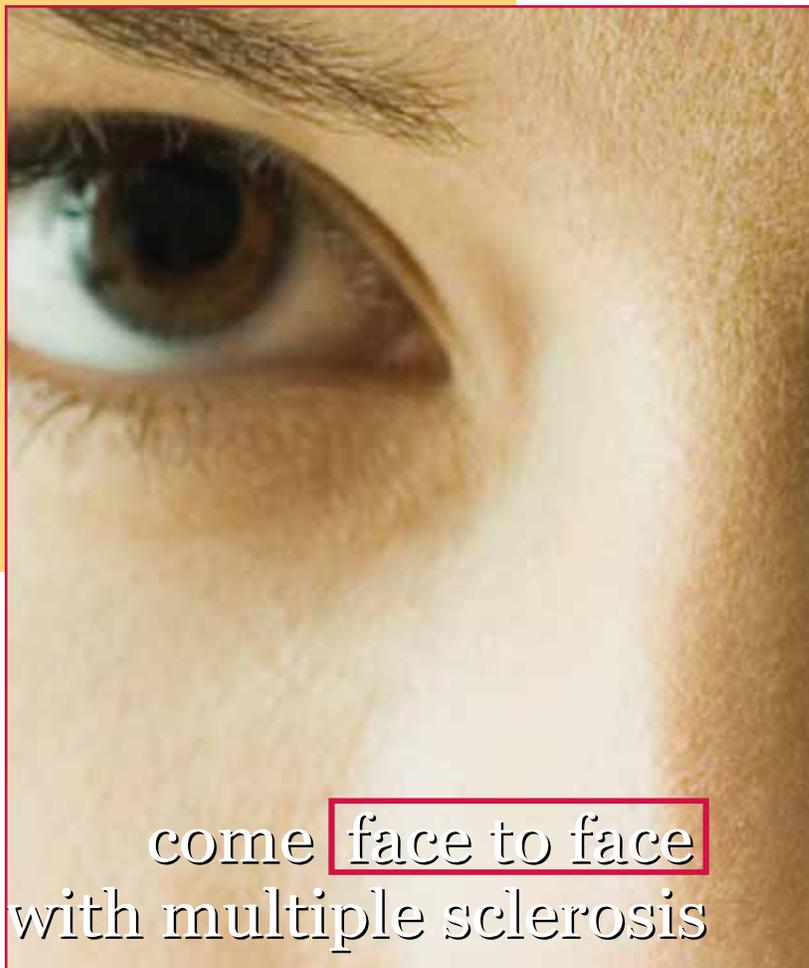
Treating the youngest people with MS

Today, there are an estimated 8,000-10,000 children or adolescents diagnosed with MS. An additional 10,000-15,000 have experienced at least one symptom suggestive of MS or a related disease, and some will go on to be diagnosed. Until recently, research and treatment have generally overlooked them.

To better serve people under 18, money from the **Promise: 2010 Campaign** has created a network of **Pediatric MS Centers of Excellence** across the United States. These centers will offer teens and children the opportunity to see pediatric experts including neurologists and neuropsychologists—all in one place. The centers will serve as central banks for information about childhood MS, and educational resources for health professionals. They will also provide insight into the best ways of coping with the effects of MS on educational, physical, and social development. Programs include support groups and education through printed materials, the phone, and the Internet. Transportation and lodging for families who need this support will also be funded by **Promise: 2010**. If anyone in your family under the age of 18 has symptoms suggesting MS, please call 1-800-FIGHT-MS for information about the center nearest you.

The first six Pediatric MS Centers of Excellence:

- **Birmingham, Alabama**—Center for Pediatric-Onset Demyelinating Disease, Children's Hospital of Alabama, University of Alabama at Birmingham.
- **San Francisco, California**—University of California, San Francisco Regional Pediatric MS Center.
- **Boston, Massachusetts**—Partners Pediatric MS Center at the Massachusetts General Hospital for Children.
- **Rochester, Minnesota**—Mayo Clinic, Rochester.
- **Buffalo, New York**—Pediatric MS Center of the Jacobs Neurological Institute, State University of New York at Buffalo.
- **Stony Brook, New York**—National Pediatric MS Center at Stony Brook University Hospital, Long Island.



**Become part of the face of MS.
Call 1-800-FIGHT-MS for
information on activities and
events taking place at your chapter.**

come **face to face**
with multiple sclerosis

THERE IS NO ONE FACE TO MULTIPLE SCLEROSIS. EVERY PERSON WHO HAS IT AND EVERY PERSON IT TOUCHES EXPERIENCES MS IN A DIFFERENT WAY.

ON MARCH 13, THE NATIONAL MULTIPLE SCLEROSIS SOCIETY LAUNCHED FaceofMS.org.

FaceofMS.org FEATURES VIDEO INTERVIEWS OF PEOPLE WITH MS, THEIR FAMILIES, FRIENDS, PHYSICIANS, VOLUNTEERS – ANYONE IMPACTED BY THIS DEVASTATING DISEASE. TOGETHER THESE STORIES WILL HELP DEFINE WHAT IT MEANS TO LIVE WITH MULTIPLE SCLEROSIS AND, IN THE PROCESS, BUILD THE FACE OF MS.

BECOME PART OF THE FACE OF MS. SHARE YOUR STORY AND VIEW THE STORIES OF OTHERS. BECAUSE EVERY STORY COUNTS.

FaceofMS.org



Talk to us and other teens about MS!
UP TO \$100 AWARD!!

Send us your stories, poetry, photographs and artwork. If we publish them, you can win \$50—\$75—\$100. E-mail: editor@nmss.org. Mail to: Teen InsideMS, National MS Society, 733 Third Avenue, NY 10017-3288.

Please send artwork (photographs, cartoons, drawings, or pictures) via e-mail or on a CD (jpeg format). We cannot return material or be responsible for original artwork, so please send a copy. We will notify you if your work is going to be published.

Please include your age, name, and address or e-mail address. We will not release this to anyone. (If you are under 18, we will need a form signed by a parent or guardian.)



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