

Teens Speak Out

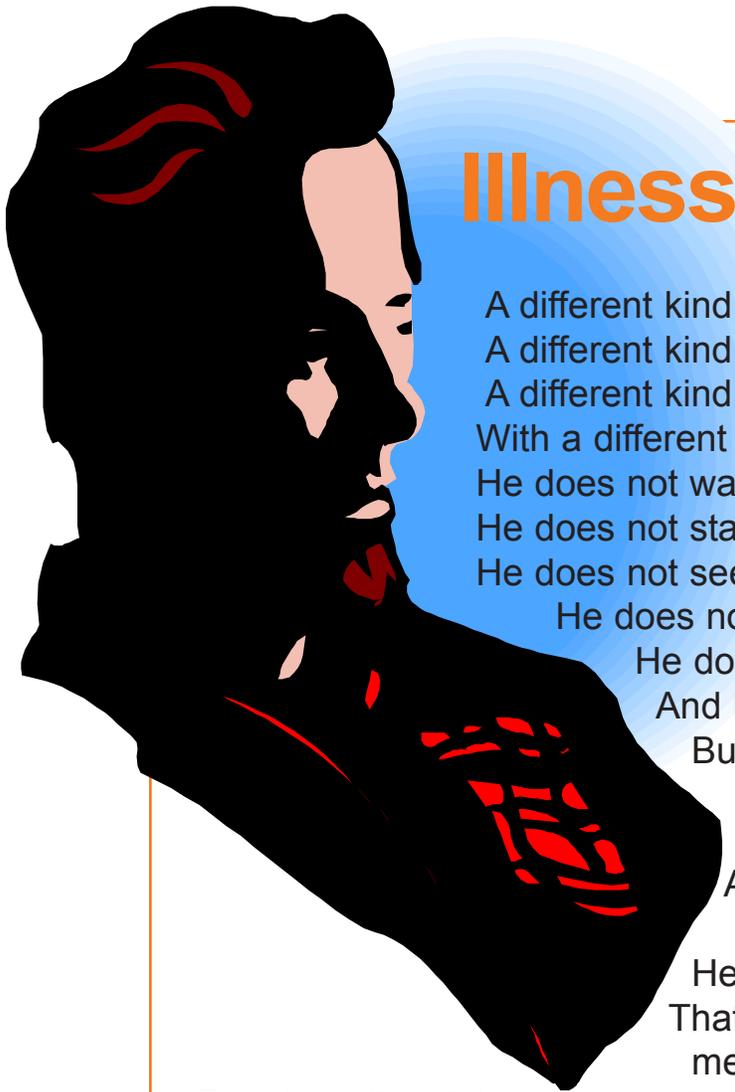


See What's Inside

- *Illness*
- *The Caregiver*
- *MS Won't Beat Me*
- *Remembering Myself*
- *A Search for Meaning*
- *The MS Walk*

teen

insideMS



Illness

A different kind of hero
A different kind of life
A different kind of world
With a different kind of strife
He does not walk tall
He does not stand strong
He does not seek for what is right
He does not seek for what is wrong
He does not cry
And he does not ask why ...

But he accepts his life the way it has turned
out through time
He smiles each day with rejoicing eyes
Along with newly accepted challenges and
new unforgiving lies
He blindly sets an example we should all follow;
That we should never view our lives as
meaningless and hollow

For strength exists in the weak
That we can climb to the mountain's highest peak
He is a miracle to me
A life that I can see,
That will live in my heart
Until death tears me apart
From him that I will forever love,
But I know he will watch in heaven above
He is my father
Struck down with an enemy by fate
But lives on and knows that it's not too late
To still love and not give in
To this unforgivable sin 🌀

by Sarah Mancini



The Caregiver

By Mandy Consdorf

My dad's MS not only affected him, my mom is greatly influenced by the things they both experience. She has to deal with all of the symptoms he is enduring. She has gone through things that she did not need to, so my dad would feel less alone, and she has made other sacrifices since he has been diagnosed. She received the Pneumonia vaccine with him and sits next to him during every treatment. She works less so she's home when he is and can accompany him to his doctor's visits. (I guess she thinks that if she doesn't go, he won't tell the doctor the truth about what is going on; she tells on him.)

Dad's biggest problems have been motor loss, tingling in his limbs, and periodic vision problems. My mom has been there through all of this. She has watched him stumble like a drunken person into walls, rub his fingers up and down his arm so he can regain feeling, stop to rest either against a table or a wall, and purposely make his hand run into a wall just so his whole body does not. Those are hard things to watch him do.

They have visited countless numbers of doctors together, and have sat through long treatments that have not worked. And each week my mom will give him a shot. To her the shots are seen as a necessary evil. She hates doing them knowing why they need to be done, but at the same time she knows that they are helping my dad maintain his condition.





In January of this year, he was given bad news about the condition of his MS. The myelin, the protective covering of the nerve fibers in his nervous system, was degenerating and there were more plaques in his brain. That was when my mom became our major support system; telling us we all had to stick together as a family. We became closer by just doing simple things. For example, we have a family dinner every night, and it is just easier for us to sit together as a family and not even care if we are doing something or not.

I was younger when my dad was diagnosed, but I can tell the difference in my mother's level of understanding. The little things don't affect her as much. "I don't fret over the small things anymore. I've realized anything can happen and I grab on to the good times," she said to me one night.

Throughout the seven years of living with MS, their relationship has changed greatly. When I asked if they are closer, my mom's reply was, "Oh yeah, we definitely appreciate each other more." They spend more quality time together I've realized. Every year they take a trip to get away from my brother and me, so they can have their time together.

Even though there are times when my mom becomes aggravated, I think that my parent's marriage has become a lot stronger than others. We try to always stick together and always be there for each other no matter how big or small something may be. Families are all about support and working together and my mom has taught me that. 🧡





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.

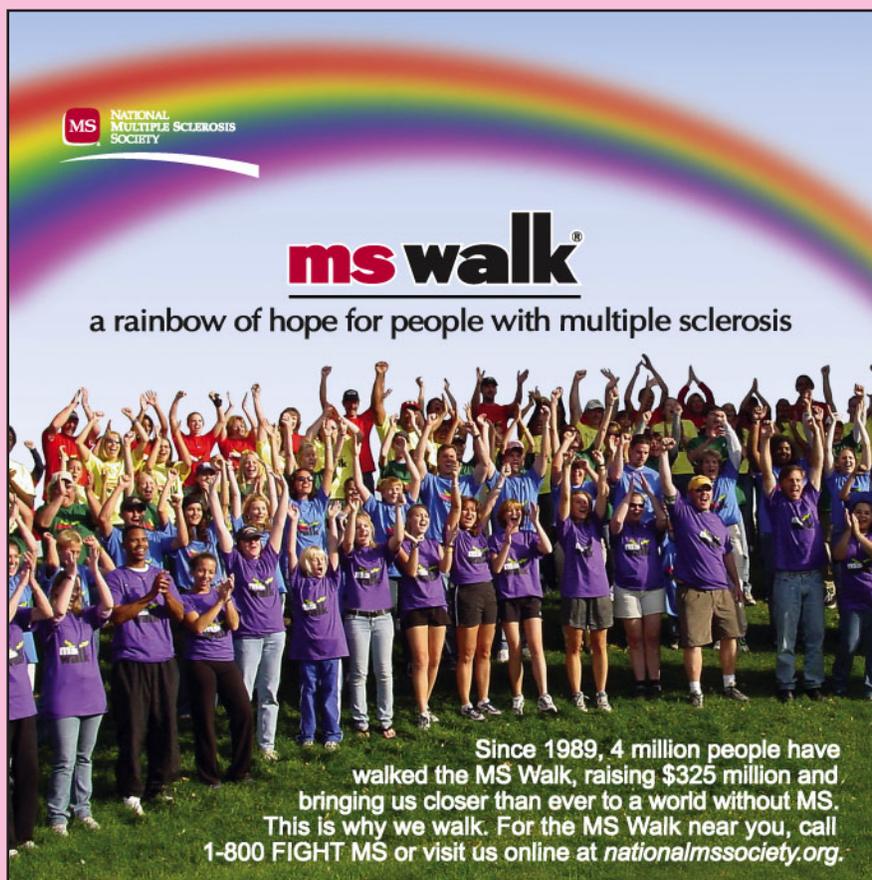
"It is just as vital for young adults who have a parent with MS not to think that they are at risk. Genetics plays a real but very small role in making a person susceptible to MS.

"Pediatric MS is rare. So far, we have evaluated 55 patients younger than 17. Thirty have clinically definite MS."

"I am so glad you included the story about the senior in high school getting MS. You have no idea how much this means to me, to see another young woman dealing with this, and school, and just life in general. It makes me feel so much better. Thank you very much, because you have made my day!"
—Megan Schaaf

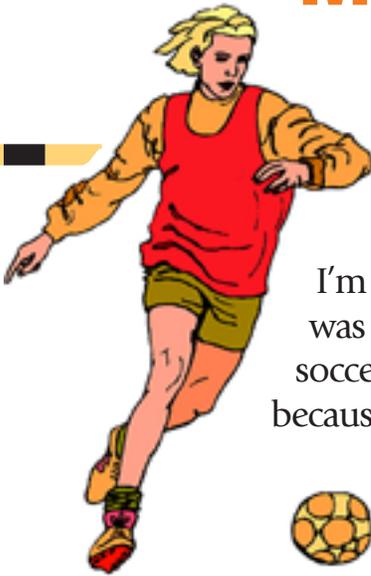
Double Vision

Diplopia, or double vision, occurs when the pair of muscles that control a particular eye movement are not perfectly coordinated due to weakness in one or both pairs of muscles. When the images are not properly fused, the patient perceives a false double image.
—Multiple Sclerosis Information Sourcebook



MS won't beat me!

By Kyleigh Hinson



I'm 15 years old. I was diagnosed with Multiple Sclerosis when I was 10. My first symptom was double vision. I remember being on the soccer field, chasing after the ball with one hand covering my left eye, because somehow I thought that would make the double vision go away.



Even then, I wasn't about to let MS keep me from being on that field. Now, 5 years later I still refuse to let it keep me from being physically active.

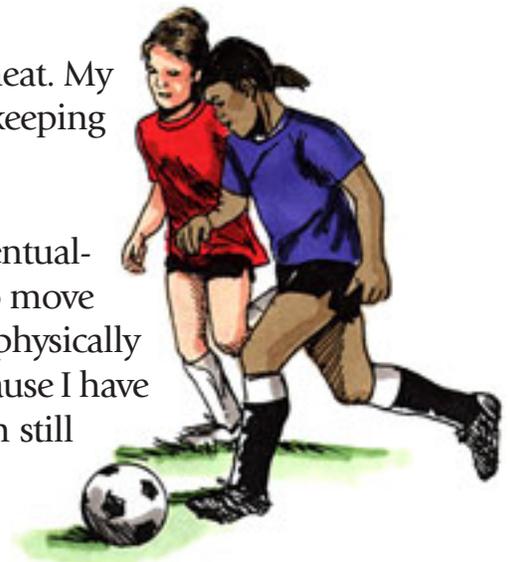
After being hit with the harsh news of MS, going through all the pain of understanding it, and finding out how it could affect me, it brought me to a cross road.

I could either get it together and do what I have to do to stay healthy, or go through denial, what I call the "I don't have MS, so I don't need the medicine" stage. I've been through both. Through it all though, I never gave up on being physically active. I believe that has helped me to stay as healthy as I am today.

I am a sophomore at a 5A high school. I am taking an AP course in history, and keeping an A average. I have a 6 minute 20 second mile time; and play select soccer and high school soccer.

It does get rough sometimes playing soccer in the Texas heat. My Mom helps. She forces me to take precautions such as keeping my head as cool as possible.

I have thought about the possibility that soccer could eventually be too much for me. If that happens then I will have to move on from my love of the game and get into another less physically demanding sport. I don't want to sit around and sulk because I have MS. I want to get out there and show **everyone** that I can still be me. 



I am a little girl.
I comb my Barbie doll's hair
While singing "Twinkle, Twinkle Little Star."
I am not the lonely teenager
who lies painfully in the dark.

I am a healthy girl.
I chase fireflies in the warmth
of a late summer evening.
I am not the 16-year-old
who takes nearly 30 pills a day.

I am a strong girl.
I run screaming through the house
as my brothers chase me in retaliation.
I am not the girl in a wheelchair
who can barely lift her arms to dry her hair.

I am a happy girl.
My laughter fills the house
as I dance to my favorite song.
I am not the girl who cries
if she forgets to take her
depression medication.

I am a confused girl.
I think about all these things
I could be and once was,
but now am not.

I am a hopeful girl.
Someday I wish to be normal again
and to hear my own laughter
as I sit with my sorely-missed,
but well-remembered, friends.

I am a girl with a disease.
It has changed my life forever
in less than a year.
But I will try hard to be ok
and learn to accept who I am. 

Remembering Myself

by Samantha Lynch



A Search for Meaning

by Jade Conlee

The most vividly recalled moment in my life was the day a Neurologist jammed an MRI film of my head into the clips of a back-light. He pointed to several spots and said, “when this is seen, it is called multiple sclerosis.” It only confirmed what my parents, both in the medical field, suspected but couldn’t believe. “But she’s only 15,” my dad said. Then they discussed medications and decided on one. The next day I learned to inject myself.

Then came the depression—not only myself, but also my family. We began to ask why. Just as the tsunami in the Indian Ocean devastated such a wide area, my diagnosis left its own devastation over my family. We asked, “How could a good and loving God allow these things to happen?” That coming from a family of agnostics!

A lot of people believe in God or some form of Supreme Being when things are going well. Some don’t even give much thought to God at all. We were shocked and resentful, but how strange that when things went bad, that’s when we looked for answers. It let us know what we truly believed.

It’s easy to lose faith, feeling resentment toward God, who is supposed to be kind. I couldn’t understand why this happened to me. Within that misunderstanding was my answer. WE cannot know the overall plan from our limited perspective.

My viewpoint had been superficial and ego based. The world changes, on a global scale and in our individual lives. We never know what changes will bring in the long run. I could have done without the

diagnosis of MS very well, thank you. I wish I could do without the shots, but this is my life now. I haven't missed an injection in a little over two years, and I am exacerbation free for almost two years.

Looking outward also helped me to cope. I started by own MS Walk team and working on my third year. I have a deal with an ink cartridge recycler to benefit the National MS Society; and people have donated cars in my name to the cause.

I don't think anyone can say with certainty why bad things happen, but I know that having MS caused me not to be complacent. Maybe I learned something. Life on earth, and my life as it was previously, is not the whole story. If you are a teen diagnosed with MS, it helps to get out and find something positive to do. 

Jade Conlee



There is Good News

The human spirit is remarkably resilient. In the face of adversity, families can flourish—marshalling resources from within themselves and their communities. Some strategies that have helped other families cope well with MS include:

- **Holding on to hope.** Hope is a powerful life force that sustains us. In the face of despair, it's a lifeline. And the marvelous thing about hope is that it is contagious. If you don't feel hopeful, seek out someone who is.
- **Maintaining a sense of spirituality.** There is growing scientific agreement about the benefits of spirituality. Having a spiritual sense about life fosters other positive traits: connectedness to others, positive self-perception, optimism about the future.

(Excerpted from *Kids Get MS Too: A Guide for Parents Whose Child or Teen has MS*, a publication of the National MS Society and the Multiple Sclerosis Society of Canada.)

Talk to us and other teens about MS!

Send us your letters, stories, poetry, photos and art. 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 email or on a CD (jpeg format). We cannot return material or be responsible for original artwork, so please send your work this way. 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 may need a form signed by a parent or guardian.)



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**Director of Publications
Martha King**

**Managing Editor/Design
Carolyn Thomas**

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