

Running the Race That Matters Most

By Sandy Pines

Jogging has always been a passion for my husband, Marshall. Running afforded him a sense of pleasure, companionship, and peace that he could not find in quite the same way elsewhere. It was not unusual for him to meet a friend early on a Sunday morning for an eight-mile run. As he and his partner would lope through the forest preserve they would chat about their successes and struggles of the past week. By the time he returned from his run he was refreshed both physically and emotionally. But that was before he was diagnosed with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. Now Sundays aren't normal anymore.

It all started about 14 years ago, when at the age of 59, Marshall experienced several falls while jogging. Prior to this he had been running an average of five days a week for more than 22

years with no difficulty keeping his balance. So when he would occasionally return with a new bruise from a fall, we wondered what might be the cause. But it wasn't until he was playing tennis one day with a co-worker that he knew beyond a doubt that his body was not right. His opponent would of course hit the ball purposely out

of reach, but Marshall found that his legs wouldn't move as he wanted them to. He also began to experience occasional involuntary "twitches" in his legs while asleep.

Determining the exact problem was not easy. After many rounds of tests and visits to various doctors, Marshall's condition was still considered a "medical mystery" for many months thereafter, which required a great deal of patience on our parts. In all, the process took about a year, from his first falls to a definitive diagnosis of ALS. We've since learned that this lengthy diagnostic process is typical for many with ALS because doctors must make the diagnosis by eliminating all of the possibilities one by one. In other words, there is no single test that shouts out: "This guy has ALS!"

ALS is a terminal neuromuscular disorder in which the motor neurons controlling the muscles in

With friends in New Zealand on Marshall's last international trip which occurred in 1992.



the body gradually weaken and no longer work. Common symptoms include problems with mobility and difficulty with speech and swallowing, which have all affected Marshall. The rate at which the disease progresses and affects muscles can vary widely from person to person. Fortunately, Marshall's form of ALS progresses very slowly but the changes are still hard.

For instance, within the first two years of Marshall's diagnosis with ALS, he went from using a cane, to a walker, and then to being in a wheelchair full time. Other adjustments we've weathered since that time include the insertion of a feeding tube, speech difficulties and the need for separate beds, among many others. Each change requires a physical and emotional adjustment on both of our parts.

Among the most difficult adjustments for Marshall has been the loss of his beloved recreational activities. In addition to jogging he loved tennis, golf, skiing, sailing, scuba diving and traveling. But he's gradually had to give up all of these. Only the memories of those activities remain. But rather than focus on things no longer possible, he has turned his attention to what he can handle — reading books, newspapers and magazines online, e-mail correspondence, searching the Internet, managing the family's finances, doing the taxes, taking scooter rides on the old jogging routes to the beach and Chicago Botanic Garden, and attending plays and concerts. He was unhappy with these substitutions at first, but a change in attitude has kept the emotional turbulence of the disease under control.

Marshall and Sandy with Sarah Duchess of York at the Les Turner ALS Foundation dinner/dance benefit in 2000.



And of course, Marshall is not the only one affected by the presence of ALS. As his abilities decreased, my responsibilities increased. I was now the one who needed to perform increasingly more of the tasks that he could not. He eventually needed help cutting his food, dressing, doing exercises and a host of other tasks. I also was his chauffeur and helped with all of his transfers in and out of the car. Neither of us liked these inconveniences: his loss of independence and the burden it placed on me. But at some point we stopped fighting the changes that were inevitable and realized that this was the way it was going to be. We needed to adjust in order to survive. That attitude shift along with the unrelenting support from family and friends have enabled us to face the daily challenges associated with this disease. And ironic as it may sound, caring for Marshall as I have over these years has actually strengthened the bond between us. We've learned to read each other like never before and developed an unspoken understanding of the other person's needs and wants.

We recognized the importance each of us plays in the other's life.

We've also grown closer as a family as a result of dealing with ALS. Our sons have been enormously helpful and generous with their time and talents. One of many examples would be our older son's creation of a software program to help Marshall speak. It also allows him to talk on the telephone and even socialize outside of our home with the use of a laptop computer. Our son has made the computer program available for downloading from the Internet to anyone who needs it at no charge. The website is www.etriloquist.com.

As time passed, Marshall needed more and more help dressing, bathing, exercising, toileting, transferring, and so on. As I tried to do it all, I was having tremendous pain in my joints. Initially, I thought it was the onset of arthritis. But after seeing a doctor I found out that the inflammation I was experiencing was due to constant stress on my joints from lifting and repositioning Marshall. So, we adjusted again and hired a live-in aide to help with most of the tasks I was doing on a daily basis, including the driving. We've used aides for more than eight years now, and I couldn't manage without them.

Another lifeline for us has been our support group. For nearly 12 years we have been regularly attending support group meetings sponsored by the Les Turner ALS Foundation. These have been invaluable for both of us. Each time we attend we take something away from the meeting that we needed at just that point in our journey. Over the years we've

The Pines family: (left to right) Sandy, Andrew (son), Jeff (son), Mary (daughter-in-law) and Marshall (front)




received many useful and practical recommendations as well as much-needed emotional support from the friends we have made there. The unfortunate but inevitable part of these new friendships though means that some eventually lose to the disease. Yet we share the grief among us and support each other through those times as well.

Through ALS, our whole family has learned about the importance of facing challenges head on. When Marshall was first diagnosed we didn't know how the disease would affect us individually, as a couple, as a family, physically, emotionally and financially. We gradually learned the impact ALS can have, and every person in our circle has coped differently.

I always knew Marshall was a determined and strong person, able to do what he set his mind on. But his response to this disease has reinforced my belief in his strength and drive. He continues to fight the good fight, pushing himself to do everything he possibly can for as long as he can, and rarely letting the disease rob him of happiness. Sometimes I wonder if the tables

were turned and he was caring for me as I battled ALS, would I be as unflappable as he. I grow more proud of Marshall and impressed with his strength as the days go on.

By caring for Marshall, I've learned about my own physical and mental re-silience. I've learned that I must be strong—and that I am able to be strong. I have learned to value those things that are most important in my life such as family, friendships, and the benefits of giving to others. I've learned how important it is to do as much as you can while you can still do it. Watching Marshall's bravery as he lives with this disease has reinforced to me that even under difficult circumstances, you can still enjoy each moment. We never know when these moments will end.

Although Marshall was the avid jogger in his earlier days, we are now *both* running a different kind of course, side by side; one that is not concerned about finishing the race as much as staying in it each step of the way. 

Challenges to mobility are an ongoing concern for many caregivers. For an excellent overview of how technology is changing the face of mobility, see our Special Focus entitled, *19 Mobility Products That Can Make Your Life Easier* in the May/June 2004 issue. You can also learn more about ALS in our Jan/Feb 2004 Special Focus. To order back issues go to www.ChicagoCAREgiver.com.

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