

Paying It Forward

By Al Freedman, Ph.D.

I remember the stuffed Priority Mail envelope with the Illinois postmark sitting on the dining room table, and I was half afraid to open it. I knew what was inside -- a friendly person named Audrey, who kindly answered my first phone call to Families of SMA, promised she would mail me lots of information. After I stared at the envelope for a while, I mustered the courage to tear it open. Inside was a pile of past issues of this very newsletter, "Directions," dated from the years 1993, 1994 and 1995. At first it was hard to look at the photographs of the children in the newsletters because I didn't want to believe our baby could possibly be one of those children. It had been just one week since Jack was diagnosed with SMA and I had not yet accepted the reality of our situation. Thanksgiving 1995 was around the corner, but it was hard to feel thankful for much of anything.

A few days after that packet arrived, I sat quietly in the dining room of my in-laws' house, reading a little at a time. There was so much sadness in those pages. Wheelchairs, memorials, hospitals, ventilators, and information about how to tap your baby's back to get the mucus out. This is all so sad, I thought to myself.

I went on to read a section of a newsletter called "Letters from our Families." Some of those letters weren't easy to read, as many of the parents described the experience of losing their children. But one letter caught my eye, from a mother whose baby was named Charlie. In her letter, Merrie Lee Peterson wrote about the joy of traveling with little Charlie, who had been affected by SMA Type 1. Merrie Lee described the many places she and her husband had taken Charlie. She wrote lovingly about how happy Charlie was to see the sites, and how grateful she was to have the memories of those family travels. Charlie had passed away, but his mother wanted the community of SMA families to know he had lived his life happily. Despite losing her child, Merrie Lee was able to look back positively on those months with Charlie.



Charlie Peterson

Now it's almost a decade later -- and until very recently I'd lost track of the Petersons -- but I'll always remember

Charlie, and I'll always remember Merrie Lee's letter. She doesn't know it, but Charlie's mother gave me a very important gift when she mailed her letter to Families of SMA. A week after we were told Jack was affected by SMA and had one year more to live, Merrie Lee taught me the importance of making the most of every single day with our children. Because she and her husband had helped Charlie experience as much as they possibly could, she was now able to find meaning while looking back at her young son's short life.

This feat felt nothing short of amazing to me. I went to bed that night thinking about little Charlie and his parents traveling across the country. I pictured the places they had been together. Somehow, I now felt like I knew the Petersons, though I'd never met them.

I began approaching my days with Jack as Charlie's mother described their family's days with Charlie. Jack was happy. We were together as a family. After a while, I began to feel lucky for every single day. And four short months after Jack's diagnosis, I found myself in Las Vegas, Nevada, at my first Families of SMA conference, still somewhat emotionally wobbly, still acclimating to this very complicated change in our lives.

And sitting right there in the row in front of me at the opening session were the Peterson's, Charlie's parents.

I was surprised to see Charlie's parents at the conference. Back then, I figured that parents who had recently lost their children to SMA wouldn't want to come to meetings about SMA. But there they were, smiling and greeting other families they had befriended in past years, friends from our Families of SMA community. I introduced myself and explained that I'd recently read Merrie Lee's letter about Charlie. I told them their letter helped me. I felt very honored to meet the Petersons. I viewed them as role models, people who faced the most adverse situation with great grace and dignity. And I secretly hoped that I would be able to somehow handle the loss of my baby the way the Petersons handled losing Charlie.



Jack Freedman at the new FDR Park in Washington - from Summer 2003 FSMA conference

Eight years later, we've just returned from an extraordinary conference in Washington, D.C., where I was again reminded of the strength of the community we belong to represented by 700 strong. Many FSMA members visited with members of Congress from their home states. Many volunteered their time during the weekend, helping with childcare, the auction, the banquet, and other aspects of the conference. As always, Audrey worked around the clock

overseeing the many details of the conference. There were Sandy & Steve Wimsatt, Barb & Gene Trainor, Karen Burton, and Karen O'Brien tending to everyone's needs and answering questions, hour after hour. Kimberly Symonds was up on Capitol Hill managing the lobbying effort. And there were Irving and Marilyn Naiditch, as always, working quietly in the background, helping wherever help was needed. Chris Spancake was very professionally leading the research conference, and Colleen McCarthy directed the childcare operation with a smile on her face for three straight days. Beverly Venedam put the wrappings, ribbons and labels on all the auction items, and the Burton family built an "accessible carnival" from scratch for all of our children.

Each of these extraordinary people, and many others, give hours, days, weeks, or months of their time in an effort to support others affected by SMA. Why, you might ask? What drives these people to work so hard to give so much to others when they have their own families to look after? I can't say I absolutely know the answer to this question for each one of these people. But I suspect that each of them, in their own times of need, were given a gift similar to the gift Merrie Lee Peterson gave me eight years ago --- a gift of hope; a gift of perspective; a gift of a role model who faced adversity with grace and dignity; a gift of time and generosity and support.

Each of our families has its own story of how we found ourselves in this club, a club we didn't choose to join. We all have stories about people reaching out to us -- with a phone call, or a hospital visit, or an email message of support. We've helped each other with equipment tips, information about doctors, ideas about nutrition, and pointers on repairing our kids' wheelchairs. It doesn't take much to "pay it forward." Every little bit helps, and every gesture of support is appreciated. Merrie Lee Peterson, with her letter about Charlie, had a positive and significant impact on my family and me. We've all received help --- and we can each make a positive impact on the lives of other families, too.

Eight years after reading Merrie Lee's letter, the Peterson family's presence is still with me as my family does its very best to enjoy each day. Eight years later, our son Jack is very much alive, and we are thankful for each moment. I've come to believe Jack carries a little bit of Charlie's spirit -- and the spirit of so many other angels we've come to know -- with him wherever he goes. To you, Merrie Lee, thank you for the gift of your letter at a time when I really needed to read those words. Because I can't possibly thank you enough for your help, I'll keep passing on your gift to others, as I am able. I'll keep paying it forward whenever I can.

Each of us has the opportunity to "pay it forward." Although we cannot be sure our collective efforts today will result in a treatment or cure for our children, we do know that supporting each other strengthens us all and improves the quality of our lives and the lives of our children. It is our obligation, I believe, to show kindness to the families and children who will be affected by SMA tomorrow, and the day after that, and the day after that, until the day comes when SMA no longer affects any of our family members.

We are all in this together. Let us each find a way to keep paying it forward.

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