

## Keeping Hope Alive

*By Al Freedman, Ph.D.*

Reprinted with permission by Quest, the national magazine of the Muscular Dystrophy Association, Volume 10, Number 1, February 2003

I'll always remember the day our first child was born. "A perfect baby!" we were told by the nurses in the maternity ward. I called our family and friends from the hospital to share our good news.

I remember the simple congratulatory message I received from a friend a few days after Jack's birth. "You are now a family," she wrote, quite matter-of-factly.

Yes, indeed we were a family, and I'll always remember the hope baby Jack brought to our lives. I remember thinking about birthday parties, ballgames, bicycle rides, and perhaps a little brother or sister, or even two. For the first six months of Jack's life, I pictured myself coaching his Little League team and taking him to Phillies games. I pictured myself watching Jack perform in his elementary school play and play in the school jazz band just like Dad.

Those early days of parenthood were full of possibilities. Exciting possibilities. Endless possibilities.

And then one day, the possibilities began to fall away. First, our pediatrician told us Jack wasn't developing normally. Then a pediatric neurologist expressed serious concern and told us to have further testing.

Four days later, a doctor stuck pins into Jack's little body and studied the readings on the dials attached to the pins. Jack cried. At the suggestion of the doctor, my wife, Anne, sat outside the examining room so she wouldn't have to watch her baby being stuck by those pins. I held Jack on my lap, hoping everything would be all right.

But everything wasn't all right. A few minutes after conducting that EMG test, the doctor told us Jack was likely affected by a neuromuscular disease called spinal muscular atrophy (SMA).

The doctor told us there was no treatment or cure for SMA. Jack would be severely physically disabled, and then he would die of respiratory complications. Babies with his type of SMA were lucky to live to age 2, the doctor reported.

The doctor explained we would have an appointment with another specialist later in the day to hear more about SMA and how we would care for Jack for the next few months. He motioned to us to stay put with Jack in the examining room.

"Take all the time you need," the doctor said. Then he walked out and closed the door, leaving us with each other, our baby and our thoughts.

But the doctor didn't leave us with any hope.

### Rebuilding Hope

In a matter of minutes, Anne and I were thrust into a parenting world light-years from where we'd started, an experience few people can even begin to understand. If you're reading these words, odds are you're in this club, too — a club none of us chose to join.

Sadly, membership in the club often demands that we check all of our hope at the door when we first arrive. Once through the door, we find ourselves wandering around, shocked and lost, grasping for direction. But how can we expect to know which way to turn if we have no hope?

Somehow many of us rediscover our sense of hope, a little at a time. And when we keep hope alive, we find ourselves feeling more positive and better prepared to care for our affected family members.

Seven years later, I feel very fortunate to be Jack's father, despite the challenges my son faces. Slowly, as these years have passed, hope somehow has returned to my vocabulary and to my heart.

But how exactly do our families reclaim and rebuild our sense of hope? From whom do we draw hope?

### **Drawing Hope From Others**

Shortly after Jack's diagnosis, still reeling from shock and sadness, I read the words of the late June Price, who at the time published a newsletter for the SMA community. In an open letter to parents of children with new diagnoses, June wrote:

"I was not expected to live, to work, to succeed. I was only expected to die . . . Today, at 48, I look back and wonder how differently my life may have been had I been given the gift of hope for a future. Because regardless of what all the 'experts' predicted, I'm still here. Parents and doctors didn't know any better back then, but they should now. Giving your child the hopes and dreams that go with a future costs nothing. Not giving it can waste a lifetime." See June Price Letter

June's wise words hit me between the eyes. Finding a way to be hopeful would be doing the right thing for Jack. I will always be grateful for June's letter and for her friendship to our family. (June Price died last year at age 54.)

Others, too, helped us reclaim and build our sense of hope one piece at a time. Through organizations such as MDA, we contacted families with similar experiences who helped us feel we weren't alone. Jack's home care nurses, therapists and teachers all view him as a person worth getting to know, and they focus on what Jack can do.

And with our move to a new community, duPont Hospital for Children in Wilmington, Del., (home to an MDA clinic) became our primary resource for Jack's medical care. Even in the middle of the night during the scariest of medical crises, the professionals at duPont Hospital somehow remain steadfast in their hopeful approach to caring for children. We continue to be lucky to have so many caring people in Jack's corner.



### **Jack's Hopes**

When we have visitors to our home, it's very easy for them to get lost in the trappings of Jack's disabling medical condition. It's easy to look at our son and see only his wheelchair. It's easy to listen to Jack and hear only his broken speech patterns and the words that can't be understood. Entering Jack's bedroom, it's hard to miss the pulse oximeter, the feeding pump and the BiPAP breathing machine.

These are indeed things Jack needs, but these aren't the things Jack is focused on. These aren't the things Jack hopes for day-to-day.

Like any other 7-year-old, Jack hopes his friends will spend time with him. He hopes for birthday presents, family outings, holiday celebrations and success with his schoolwork. Jack hopes for new computer games. He hopes we'll take him places with lots of space to zoom around in his power wheelchair. Jack hopes his little sister will be fair and take turns. He hopes to go swimming at the pool. And he hopes Dad will come home from work in time to give him a bath.

So it's Jack himself who now shows us the way, with his own sense of hope as our inspiration. Despite the many challenges he faces every day, Jack is a happy, motivated little boy who hopes for many of the same things other kids hope for. And seven years following his diagnosis, we're indeed grateful to have Jack sharing his hopes with us.

As June Price implored us to do, Anne and I approach every day of Jack's life with hope for his future. We hope for understanding friends. We hope for skilled and compassionate medical professionals, for accommodating special educators and therapists, and for the energy to carry on day after day with our family's version of "normal." We hope for Jack's continued health and for the day researchers will discover a treatment or cure for SMA.

But most importantly, we hope for Jack's happiness. We would like Jack to continue seeing himself in a positive light.

### **New Rules**

I've come to realize that membership in our "club" demands something quite different from what I experienced in those first moments — back when I checked all my hope at the door. Seven years with my son have taught me that it's my job to help change those membership rules. I've come to believe it's my job to follow Jack's lead and hope for all the good things he hopes for.

Following a remarkable recovery from a harrowing hospitalization, one of Jack's critical care doctors told us, "Jack's a fighter."

All of us who find ourselves in this club know a fighter. But our loved ones cannot fight without hope, so it's up to all of us — family members and professionals together — to keep hope alive.



Albert Freedman, Ph.D., is a child and family psychologist in private practice near Philadelphia, PA. His son, Jack, is affected by SMA Type 1. You are welcome to contact Al at [freedman@fsma.org](mailto:freedman@fsma.org)