

## 25 Voices of SMA The Potter Family



### Who are we?



We are the Potter family of Massachusetts. Mark & Laurie, Murphy (5 years old), Anders (2 years old), and Marshall (forever 4 months & 6 days old).

*Our purpose in life has been defined by spinal muscular atrophy, and of course by our little boy Marshall. For someone so young who never spoke a word, he has been our greatest teacher.*

### Why did we become active with FSMA?

Almost immediately after Marshall died in December of 2002, we began fund raising for Families of SMA. In the beginning, it was a survival mechanism for us. We needed something to occupy our minds and our hearts to get through each day without our son. We began attending local events and met many other families who had also been touched by SMA. Years later, we continue to do what we can to help Families of SMA so that they in turn can continue to help others.

### What is our contribution?

We try to work behind the scenes as much as we can. We try to offer as much local support as we are able to. Through our generous helpers and sponsors, we have been able to sponsor the yearly FSMA conference. We have purchased toys for the children's rooms at the conference. We have also been known to purchase equipment for families such as car seats and car beds, wheelchair lifts for vans, portable battery units, positioning devices, etc. On a rare occasion we have funded funeral and burial services. We also answer the phones for the New England chapter of FSMA and frequently speak with parents of the newly diagnosed, and those who have been recently bereaved. Most recently, along with the Reilly family (also of Massachusetts) and under the direction of the Strong family of California, we were able to make a sizable donation toward the efforts of Dr. Keirstead's stem cell project. Even though our own son has been gone for quite some time, that cure is still so important to us! We continue to do what we can to support research and prevention of SMA.

### What do we like about FSMA?

The one thing that sticks in our minds is how each and every family is held in high regard and remembered by everyone involved with FSMA. We have always been people with names; never a number or just another case of a family whose baby has SMA. Each family has been embraced and supported. There was a time after Marshall had been diagnosed that I called the national office for something and spoke with someone there. Unaware that they had any knowledge of us at all, I said into the phone "hello, my name is Laurie Potter" and the response on the other end of the line was "Oh, you are Marshall's Mom!" I was surprised to say the least. Yes, I was Marshall's mom! And 7 years later, to everyone at FSMA, we aren't just Laurie and Mark Potter. We will always be Marshall's Mom and Dad.