



## Q & A with Melissa Gilbert

### 1. How and why did you become interested in pediatric issues?

It's kind of a long story. I have, since I was a tiny girl, dealt with death. Or death has dealt with me. I lost my best friend, when we were four. I lost my Dad when I was 11. My first dog when I was 12. My great Aunt Mary when I was 13. Members of the "Little House" crew ... it is no secret that the death of Michael Landon affected me deeply. The list of loss ... my personal one goes on and on.

It's also really amazing to me. When I look back at my life how, repeatedly, my path has crossed with that of a chronically or terminally ill child. I have this thing, whenever I visit someone in a hospital or if I am shooting in a hospital I connect with the head of Public Relations there to see if there are any patients who might want to visit. Nine times out of ten ... and this has gone on for decades, I end up on a pediatric oncology floor.

A few years ago, when I was the president of the Screen Actor's Guild (SAG), I heard about a boy named Dustin Meraz. He was at Childrens Hospital Los Angeles (CHLA) and was dying. He wanted to be an actor. I was asked to give him a SAG card. Well, we got him his honorary card and we had a ceremony for him at CHLA. It was one of the best days of my presidency ... maybe one of the most important of my life. Dusty died two weeks later. I wear his words on my wrist "Today is a gift, have fun" ... he's right, you know.

I was asked back to CHLA for their annual holiday party for the kids on Dusty's unit. That day changed the path of my life forever. That was the day that I was hit by the blonde tornado, Lori Butterworth, co-founder of the Children's Hospice and Palliative Care Coalition. She asked for my help. She's a tough woman to say no to actually, it's impossible to say no to her; especially when she's got you pinned up against a wall.

A little while later I had lunch with her and her co-founder Devon Dabbs. I listened to their stories in awe and horror, so moved by what they told me. So many statistics and case numbers and long named diseases but underneath all of that there is a child. A child who needs help. A child who may know that he/she is dying. That child has a family. That family needs help too. The medical costs alone are staggering. Not to mention the tremendous financial and emotional burden these families must carry.

I myself have a million dollar baby ... that was what it cost to keep my son Michael alive for his first year. Michael was born prematurely. The first year of his life was ... extraordinary. Like a war almost. Thank heaven for the SAG health plan! I look at him now, and I can't believe he was ever so frail! Michael, who just started sixth grade, is responsible for giving me my motto, "Love, trust, hope, and believe."

**2. What are the three main things you have learned from children, parents, and professionals with whom you have worked?**

The children I have met have a purity about them; an honesty that comes from not having a lot of time to deal with trivial things. They are open and straight forward and they have a courage that borders on overwhelming. They inspire me to try to live my life efficiently, openly and with love.

Additionally, I am regularly inspired by the people I work with. Their tenacity and generosity of spirit are unparalleled.

Finally, I'm continually blown away by the level of integrity and dedication that each member of the hospice movement brings to the table each and every day. Your collective efforts are breathtaking and make it an honor for me to serve as board president of Children's Hospice and Palliative Care Coalition and as the national spokesperson for Partnering for Children.

**3. What is your main goal for Partnering for Children?**

To get the word out and increase support for our shared vision. The best way to do this that I can think of is to tell our stories. We must make people aware of what it is like to care for a dying child with little or no support. These families need nurses, social workers, spiritual advisors, grief counselors, and volunteers to go do laundry ... anything! Everything!

We know that many children who die in this country die in uncontrolled pain. Unnecessary pain because they don't have access to hospice care when they need it. This is disgusting, frightening, and wrong.

We at Children's Hospice & Palliative Care Coalition aim to change that one child, one case at a time until all children who need hospice and palliative care can get it and their families are not left to suffer alone. It is our great hope that working with NHPCO through the Partnering for Children campaign will get us even closer to our vision.

**4. What is your message to the professionals about pediatric palliative care (i.e. hospice, palliative care, coalition folks)?**

Honestly, I think you people are angels here on earth. My message is simply to keep up the good work and please do everything in your power to spread the word about the work of pediatric palliative and hospice care and Partnering for Children.

Together I'm confident that we are a movement that cannot be stopped in bringing justice and care to those who most need our help.

**5. What personally keeps you motivated?**

Helping people fills a part of my heart. I have always felt that children need help most of all.

I think that everyone has a thing that they do best. Some people can help take care of the elderly. Some are moved to work with animals, you name it. So here I am this public figure with an ability to deal with and talk about death and end of life issues and a strong desire to help children. The clearest choice for me is pediatric hospice work.