

The Parents' Reaction

SUZANNE ROWDON, *President, Northern Virginia Guild for Infant Survival*

As I sit here it appears to me that most of you are aware of SIDS through your profession and education. My awareness came like a lightning bolt one sunny afternoon when I was getting ready for Thanksgiving dinner. It left a wound that is very slow to heal and my reaction from that continues to this day.

It was 18 months ago that I had a bouncing 7-month-old daughter whom I had put to bed for her afternoon nap. I went in one hour later, which was halfway through the nap, or should have been, and found her lying on her stomach looking very relaxed. She had the blanket over her head, which was not uncommon. I reached down to pull it back into place and my heart fell—she didn't feel right—I screamed for my husband. He came running and administered CPR while I called the rescue squad. They were around the corner and were there in about one minute and rushed the baby and me to the ER. My husband brought the car as we assumed that the three of us would need a ride home. While I was waiting for him, they made me fill out forms. I waited in the "family room." No one had mentioned the word "dead," no one had stopped doing anything in the ambulance, they were working on her constantly. I assumed everything would be all right. It didn't occur to me that my child could be dead—that thought had not entered my mind—I was wondering what had happened, how long she would be in the hospital, what they were doing. I stood up and walked to the door of the family room and as I looked out the fireman who had brought us in was leaving. He saw me walk out and he turned around. He had tears in his eyes. I'll never forget those tears and I'll never forget the look of the doctor and the nurse when they were walking towards me. I don't really remember what happened after that. I remember the words "did all we could." I remember a piece of paper with a name of an organization and the words Sudden Infant Death Syndrome. The doctor took the time to tell us that there was no cause that he knew,

nothing we did had caused it. I didn't really hear. I didn't see how it could be nothing we had done; it was my baby, a baby in my care. I was responsible for feeding her, putting her to bed, getting her up, making sure she was clean, making sure she was healthy; I was responsible for her and if she died, I didn't see how it couldn't be my fault. The reaction of a parent at this point, as did my reaction, depends a lot on what happens and on the people who deal with the parent. I must say that I was a very fortunate parent; I was treated with respect by very informed people. Our rescue squad knew SIDS, knew that what they said would have an affect on me, not only that day, but the long, lonely nights ahead. The ER personnel didn't just tell me that I was not going to have a baby to take home, they took the time to explain what SIDS is and isn't, hoping that a little of what they said was going to sink in. They gave me the name of a group to contact. Unfortunately, the information was outdated, but I was lucky in a way some people aren't. A friend of mine took her baby to the ER and the resident looked at it, saw some froth around the mouth and said, "Looks like a baby who spit up and choked on it." My friend will never forget that. An autopsy proved his diagnosis wasn't right, but she'll never forget it. It is routine that a policeman must investigate unwitnessed death. Here again I was fortunate; I don't remember talking to him. He was aware of SIDS and he knew it could occur; he did not assume that it was a homicide. My pediatrician had been aware of SIDS and its management and contacted us immediately, giving us some time to pull ourselves together and let the realization set in. After being at the hospital I don't remember how I got home. I remember making funeral arrangements, but all of a sudden I was in a room looking at a bunch of baby clothes that I had to put away, that I didn't need. As I walked to the kitchen there were baby bottles, bottle brushes that I didn't need either. Luckily for my husband and me our pediatrician called and explained what was go-

ing to happen, that there would be an autopsy, that we would have to wait and that we would be discussing the autopsy. Two days later the reality had sunk in and my pediatrician said, "Let's go over this autopsy." I had been wondering why the baby was gone.

The most important thing to me at this point in terms of a reaction was dealing with other people, people who didn't know that my daughter had died. It's hard to tell a neighbor that the baby I had over at her house yesterday was dead. It's hard to say dead. You look at their faces. What do they think? Some weren't familiar with SIDS. When you say, "My baby is dead; she died of SIDS," they look at you like, "What's that?" or "I've heard of that. That means your baby suffocated. Were you taking a nap with her?" You have to explain what SIDS is because they look at you with disbelief. I was lucky in that I was able to get in touch with other parents who had lost a baby to SIDS and it gave me the opportunity to talk with people who could say, "I was there." One of the hardest things for me was to tell people that my baby was dead and for them to say "I know how you must feel." Like hell you do. You don't know what it's like to lose a baby, to sit there at night and want to rock the baby to sleep, or to wonder if the basement door is closed and to realize that it doesn't matter anymore. I was able to talk with parents in the Guild for Infant Survival. They said it was hard, but they had made it and they knew I would too. They were there in the night and in the morning.

As time went on I was able to deal with reality. Everyone began asking when I was going to have another baby. Everyone was waiting to see what I was going to do. When you do decide to have another child, your grief does not end; you are still a SIDS parent, your future chil-

dren and pregnancies are affected by that fact. You go to your obstetrician and if you're lucky, he or she will realize that this is going to be different. A SIDS parent will react differently to another pregnancy, with all the worries that every prospective parent has. Will my baby be all right? Will it be deformed? No one can say to you that only 1% of the babies born have problems and it probably won't happen to you—it already has. You have memories tucked away. Once you have gotten yourself together it is easy to push memories to the back, things that are difficult to think about. All of a sudden the emotions that you have buried are there; you want to be excited about your new baby, but you can't bury again the old emotions. You get excited at the point of birth; a whole new baby. You have this child in your arms and maybe it looks like the child you lost and maybe it doesn't. In my case they were identical—different sex but almost the same face. You begin to wonder how long this one is going to last. Is it something you can look forward to? Are you afraid? I was and I think most parents are. I think now the more you know, the more you realize that there are certain risks. No one knows the answers, but at least someone knows the correct things to ask. I think many parents are now asking the questions; they want to talk about apnea, about near-miss. SIDS parents are asking questions and the questions have to be dealt with.

I know there will be a time when I can walk into my son's room and not wonder what I'm going to do if I find him dead. My son is 7 months old, one day older than my daughter was when she died. The reaction to SIDS certainly doesn't end when the baby is two months dead. It doesn't end when you have another baby. When it ends, it is different for everyone.

The Guild for Infant Survival

JOANNE HESBACH, *Past President, The Guild for Infant Survival of Central Virginia*

The Central Virginia Guild was started in 1976 by three families who did not know each

other. We had one family who had lost a child to SIDS and two families who had babies on mon-