

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-

itors. We all shared the same goal—we wanted to see an end to SIDS some day. We joined together and started a guild here with tremendous cooperation from the medical community. We worked mostly with Dr. David Draper and Dr. Edwin Myer.

The Guild's functions in Central Virginia are a little bit different from the other guilds throughout the country. Our SIDS families do a wonderful job talking to the new SIDS victim parents. We are notified through an Emergency Room, a physician, a nurse or a friend to call someone. If I get the number, I pass it on to our SIDS family, because these parents need someone who can say, "I've been there." Our SIDS parents are available 24 hours daily, so if a parent needs help all he or she has to do is call. We make follow-up phone calls and we visit the families.

A second function of the Guild here is that we are called when a baby needs a monitor. We get our calls strictly from the physician in charge, usually Dr. Draper or Dr. Myer. It is only through a physician's suggestion that the Guild gets involved. Our chief function is to help the parents secure a monitor whether it be through the monitor program that was established at the Medical College of Virginia in August 1977, to whom we have donated six monitors, or through insurance companies. We show the families how to operate the machine, where to put the electrodes on the baby, how to rearrange the furniture in their house so that when the alarm sounds they don't run into a chair or trip on a rug—we just give them little hints and lots of support.

Another function of the Guild is that we provide speakers for civic, church or any community organization. We try to make the community more aware of SIDS, what it is and what it is not. We tell people how to react to a SIDS death when it is a family member or a friend, what to say and how to support them.

Sue* mentioned the rescue squads and police departments. These are usually the first people on hand after a SIDS call. What they say can make or break the parents. If they are suspicious at all because of the baby's appear-

ance, or make any remarks, such as, "what did you do to the baby?" or continue to question the family, they can heighten the guilt complex, and instead of helping the situation, really drive it into the family. The parents are going to be so much more guilt-ridden that it will take much longer to help them. When my son, Michael, was found, he was cyanotic and completely limp; I thought he was dead. I did not know he was just on the way out. I called my father-in-law in New York and told him Mike was dead and that I had killed him. That is as far as I can identify with a SIDS mother, because I had no way of knowing he was still alive until my husband yelled from the other room that he was breathing. My husband told me three years later that when the detective was questioning us he had asked if I had really beaten the baby up or had I tried to suffocate him. It is a good thing he didn't ask me that because I'd probably be in the State Mental Hospital by now. Our Guild is helping the Police Departments avoid situations like ours by showing films on how to handle such a call and what to say and what not to say. We've also donated video tapes to the police departments entitled, "SIDS—The Role of the Police Officer," and these films also show them how to be a little more compassionate. We have also had a lot of cooperation with Dr. Marcella Fierro's office.* She has sent our brochures to new SIDS victim parents so they will know we are here, but we do not push ourselves on the parents.

When we are called by a SIDS family, we invite them to attend our meetings. Our meetings are open to anyone who wants to see an end to SIDS. We try to show the parents that they will make it after their baby dies—it will be hard, but they will make it. Our meetings are not mourning sessions. We try to look on the positive side—we want to keep the research going. We feel our meetings are good for families and we encourage people to attend them. A lot of people wonder what goes on at a SIDS meeting, but we are just like any other organization; we plan our meetings and we plan our year's activities. We are here and we want to help in any way we can.

*Suzanne Rowdon, a SIDS parent and President of the Northern Virginia Guild for Infant Survival.

* Office of the Chief Medical Examiner.