

## MedConference 2010

### Nurses' session

**Enrico Grugnetti, NS:** So, good morning again. What we want to do now is basically to continue the work we started this morning. I would like to start with a provocation: I have news and the news is that the patient doesn't exist. And this seems banal but it is not. The patient is a person in front of us. Same humanity, same needs. And talking about evidences that are evident, it is. But still, we forget it. We often forget it because of the education we receive, the professional education we receive, because of the environments in which we work and because of the scrubs we wear. And that often they become boundaries between us and the person in front of us. Often we forget there is not professionalism without humanity, like we were saying this morning. And that's an evidence. In fact, health care systems in the western civilization, they were not born from science. They were not born from doctors. They were born because at certain in point in history certain people started to take care of people in needs: widows, orphans, sick people. This is how hospitals in our civilization were born. And these people started to take care of people in need because they were moved how we said, as we heard this morning, because they were moved by their needs. What we want to do now is exactly true experience, talk about that, go deeply in the real excellence of our professionalism. We will do it through three registered nurses, colleagues of mine. And they will present themselves and they will present clinical cases, in which they will basically tell us what happens when our humanity meets the humanity of the other in front of us. We start with Debbie Acevedo.

**Deborah Acevedo, RN:** Thank you. I want to thank Elvira for inviting me here. She is a neonatologist at Children's Hospital of New York where I work and she's a good friend of mine, and it's a real privilege to be here this morning. I was privileged to come to the conference last year and I was really really moved. And when she asked me if I would speak this year – I'm not a speaker, I'm a nurse – I accepted her invitation because I was so impressed with the topics and with the ideas that come out of this conference. And so I hope that you will be able to receive what I have to offer today. Like I said, I'm an assistance head nurse in the Children's Hospital of New York, here in Manhattan. And I've been working at Columbia University for about 31 years now. I've been working in the neonatal ICU all of those 31 years, and I've been an assistance head nurse for only four of those years, all the other years I remained a bedside nurse, and I have always said, and I continue to say I love my job. I love working with my patients. I work with critically ill babies and so we do open heart surgery, we do ECMO, we take care of patients who are dying, who come in from other parts of the world to be taken care of, and it's a real privilege to work there. I have been involved also as an ambassador to South America and recently to Italy. So ciao to all of my Italian friends! I loved Italy. And I've been able to go to teach in these other countries how we take care of our premature babies. So that's also been an exciting part of what I have been able to do. My job, I really consider it a calling. I knew from very young that I wanted to be a nurse and that I was supposed to be a nurse and now that I am a nurse I know that this is where I belong. As I was sharing with the doctor who spoke this morning so beautifully about his life, that life and our experiences really do speak to us. And if we listen closely it really is the voice of God that speaks through us, through our patients and through our experiences. This morning I'm going to speak to you about a case study, a family that I took care of, that I was able to really learn from and as a result find good friends, lasting friends. Florence

Nightingale once said “nursing is a high calling. The honor does not lie in doing all things perfectly. Honor lies in loving perfection, consistency and being ready to say I will live to deserve to be called a trained nurse.” This reflects the passion the respect and the empathy she had for her patients. So it is no surprise to see that, to read that every person’s face soften with gratitude at the sight of her. Only those who have touched lives in this way can truly appreciate this statement. Einstein once said “No one cares about what you know until they know that you care.” And in the Bible, in Galatians, Saint Paul says “Bear one another’s burdens and so fulfill the law of Christ.” So what do our patients want from us? As I said, I have been a neonatal nurse for 30 years and I have practiced primary nursing for most of those years. I have made lasting friendships with many of my patient’s families. And in the NICU I am one of the few nurses who speaks Spanish so I also have the privilege of translating for the medical staff and for the Spanish speaking parents. The definition of the patients in the NICU is the baby and the parent. So we have the responsibility of taking care of not only the patient but also the family. And this is how it should be. I’m going to share a case study of one of my favorite patients, who in this occasion was Spanish speaking, and they had me come to meet them for the purpose of translating. Alejandra was born at 30 weeks, with the birth weight of only 800 grams. After a pregnancy complicated with maternal hypertension, and despite a very low birth weight, her first few days of life were unremarkable. She came to us from an outside hospital and so she was intubated when she came to us but very soon we put our babies on nasal prongs CPAP which is a system of respiratory support that one of our doctors, Dr. Wung who’s renowned for this, has taught us how to use. As she was growing and being fed slowly, still needing some intravenous nutrition, but stable, at two weeks of life she was diagnosed with a very severe form of necrotizing enterocolitis. She was in critical condition. She required life support and immediate surgery. The day I met them was the day of surgery for Alejandra. The mother Sandra was alone and very distraught. I sat with her in the family lounge, and I asked her how I could help. She asked me to call her husband and her pastor, and so I did. And by the time her husband came, she was faint and really in need of medical attention herself. We called EMS but she refused the help. She was able to settle down to what would be a very difficult conversation. The surgeons came in to talk to her about what they had found. It was not good. Alejandra had almost complete necrosis of the stomach, small bowel and colon. They were recommending removal of support and comfort care. Another way to say, let her die. After many questions, hugs, and prayers, I encouraged them to go home to review all that they had heard and to come back in the morning with the decision. The neonatologists were also preset and gave their support and suggestions. Dr. Parravicini who would soon be their primary doctor, which is not so common in our unit, was supportive and empathetic. She told them that there was no rush to make a decision and helped them understand what was happening with their daughter. The next day they came in with a decision that they had made with their pastor. They could not remove life support, and they wanted to help their daughter to live. This is a picture of Alejandra before she went for surgery, her mom is holding her arm. And this is something we used to teach the parents very quickly when they come to the unit. We want them to be to be a part of the care, and we tell them that their children know their voice, know their smell, know their touch. It’s very different from the doctor’s touch, very different from the nurse’s touch and so we encourage them to touch them. So Dr. Parravicini, myself and Alejandra’s caregivers fully supported the parents’ decision for several reasons. Alejandra’s condition was critical and her chances of surviving were minimal, but not impossible. Also Alejandra was a tiny, premature infant and as such even in healthy conditions she would have needed a basic life support because her lungs were still immature.

Lastly, but more importantly, Alejandra, as all of us, had a destiny with a beginning and an end defined by someone else, not ourselves, not her parents, not even her caregivers. And for this reason, we decided with her parents to follow her clinical status to identify if and when her last moment came without planning ahead of time. Her conditions continued to worsen. Few days after surgery, the surgical wound developed dehiscence, draining necrotic and purulent material and she was treated with wide spectrum antibiotics. She required blood and platelet transfusions, and we simply observed her day by day serving her life as it was. Alejandra's medical and nursing plan of care focused on the real needs of Alejandra including basic life support without escalation of care and attention to comfort. For instance, from a medical point of view we decided to have minimal routine blood drawing and we instituted a careful plan of pain management. We cleansed her wounds daily, giving careful attention to sterility so as not to expose her to any additional bacteria. We taught mom and dad how to change the dressings too. Positioning every three hours was important to do, to help her develop normally, and I taught mom how to hold and calm the baby. And of course, this was once she stabilized and she showed us that she wanted to live, and she was able and strong enough to come off the respirator and go on to CPAP. Passive range of motion was also offered by us and taught to parents as well as massaging and kangaroo care which consists of skin to skin care, where the parents and the babies are touching each other skin to skin and it helps them to develop and to improve their health. So all of our attempts and all of our care really were focused on serving life to her and not helping her to die. We would also allow their visitors to come and to visit with Alejandra when they were not able to come in. Mom provides music CDs for Alejandra, and I remember I would play them, and I would tell the parents, I would play them all day long if you want me to. And so I would. I would play her the music that she provided, and she was very happy about that. This gave continuity and the care that mom and dad wanted to provide for their daughter. We wanted to support them in these efforts. In showing respect for their needs without passing judgment or imposing our own opinion help this family cope with their reality. I remember there were many other coworkers of mine who saw the impossibility of this situation and would ask me, "Why are you doing all these things? I mean, why don't you just tell them this is impossible?". But my attitude was we need to support the family and their wishes because this is their baby. And because I know that life, as I said earlier, is not determined by us, it's determined by someone else. And so we have to kind of follow life for whatever signs it shows. And in Alejandra's case, the signs showed that wanted that she chose life. Two months after this situation, and to the surprise of everyone, Alejandra started improving. Most likely the spontaneous drainage helped the healing process and eventually the wound healed by second intention. Alejandra wanted to live and soon we were able to remove her from life support and wean her to CPAP. We continued to offer a care focused on comfort and we began to involve the parents in the daily care of their child. I remember one mother's day, I took a footprint of the baby, and made a small card to give to the mom. It simply read: "Happy Mother's day to my wonderful mommy". She was moved to tears that I would take the time and the thought to do something so personal for her. Really, it was nothing in my eyes, but it was a big thing in her eyes. We taught them how to change the abdominal dressings over time, how to bathe her, how to hold, how to organize her, how to calm her, and even how to change the complex *Broviac* dressing. They were able to bond with their infant and pick up on small changes in her behavior. I believe that this helped the baby to improve faster and to strengthen the family's ability to trust us and to trust themselves. When Alejandra, at the persistence of Dr. Parravicini, returned to the OR for a second exploratory lap and almost two and a half months after the first, a miracle was granted.

Alejandra was found to have viable stomach, duodenum, seven centimeters of jejunum, and an intact colon, which was anastomized to the remaining small intestine. Even the head of pediatric surgery did not anticipate what he had found. And I just want to say, as a little side note, that Dr. Parravicini was also very positive in pursuing the life that was in Alejandra. As a matter of fact, when the pediatric surgeon opened her up, he fully expected to find exactly what he found the first time which was a completely dead bowel and no stomach. So to his surprise and really, to ours, we were so grateful that God had performed this miracle for her. After that she continued to improve although her intestinal function continued to be quite limited. She was with us in the NICU for almost six months, and she was able to go home with a *Broviac* for parental nutrition at night, a G-tube for continuous feeds, and with the support of a home nurse. As we prepared them for discharge we went over and above the call of duty, translating information into Spanish for them, writing letters to the insurance company and healthcare agency to make sure that they provided an at home nurse, ordering supplies, coordinating doctors visits, and even purchasing a stroller for Alejandra. We celebrated Alejandra's first birthday in Elvira's house, and her second birthday at Chiara's home, an Italian neonatologist friend of Elvira, visiting from Italy, who's here with us today. She is now two and a half years old. You see, Elvira and I began to build close bonds with the family, especially because mom spoke perfect Spanish and perfect Italian. Dad spoke Spanish and English. I spoke Spanish and English. Elvira spoke Italian and English. The baby spoke baby, and we all spoke to God. So in conclusion what do patients want from us? Number one, to be healed. Number two, to be cared for in a compassionate way. To be given expert information about the reality of their illness. To be given timely and meticulous personal treatment. And to feel connected to their caregivers. Compassion means to suffer with, to the extent that we are willing to give consistent compassionate care, will determine the level of satisfaction our parents and our patients will have with us. Having a significant impact on a patient sometimes requires more than just the textbook approach to illness and I think that's something that's been brought out already. It requires that we go the extra mile and provide extraordinary approaches to care, asking ourselves, "What would I want in this situation?" This can provide us a window of opportunity into needs and to how they can be met. Thank you very much.

**Veronica Busman, RN:** My name is veronica and I'm at NYU medical center, I work in medicine, and I've been working for three years so I'm a baby in nurse years. I work with usually elderly people, with adults in general critically ill, and we have a step down unit stroke unit epilepsy. So why did I became a nurse? I'd like to start with that because that has to do with what is a person.

There were two episodes. One was a friend of mine who was a nursing student, it was nine years ago and she told me that being a nurse was getting your hands dirty with human stuff and she meant that literally, and figuratively. And I asked her "is it ok if I'm sensitive? Like if I cry?" And she told me "You'll even be a better nurse. You know, a good nurse cries because it's a sign of one's humanity. The second thing happened when a friend of mine got sick and had to have surgery. He just had his gall bladder removed. Everything went well. When I went to visit him, he just looked really like dirty. He needed a shower. And I thought "well who does these things that are so basic but make such a big difference in an ill person's life?" The nurse. So that's how I went off to nursing school. And so I'd like to talk to you and illustrate these small but great needs that constitute the person and recognizing and serving them is my job. My patients are actually the ones who teach me how to do my job and not just books.

So the first case is that of a young woman. She was in her thirties; I'll call her Katia, that's not her real name. She was admitted to our unit for altered mental status. And she had a prior history of liver failure that had been diagnosed a few months prior to admission, and she couldn't be cured because she needed a liver transplant and due to religious reasons she was not a candidate for it. So when she was brought in, she was confused but awake. I gave her medication and food and I remember she really loved grapes so I fed her grapes and she basically had regressed into a child-like phase where she would just make noises. She was like an infant basically, and she at first was verbal and then became non verbal and went into a catatonic state whose etiology really no one figured out, and no one could really figure out. They put her through so many tests and nothing was showing up. So what was going on in her brain was really a mystery to the doctors. And I had taken care of her before this second admission and so I gotten to know her and her family, and they were really really nice people. They were Russian so they didn't really speak English very well. Her kids were really sweet kids and really bonded with them. I took care of their mom and so when I had her as a patient the second time, I felt that I knew who she was and I saw this human being trapped in a body that just couldn't communicate. She couldn't. Her eyes were staring, and at first I thought they were staring at me and then they just went into void. You know, she really didn't track and was totally unresponsive. And for me the question that aroused was "What is her purpose?" "What is the purpose of a person like that, an adult woman who's lying in bed all day and she's unable to speak?" And I was happy to take care of her because undoubtedly in my eyes she had a value. I knew her. I knew who she was. I knew the woman hidden in this body that was completely unresponsive. And she was great. I knew she was a great woman and I knew I could serve her in this need. So she needed to be turned position and sooner she couldn't be fed anymore so she had a G-tube and her health couldn't be restored, but yet like I didn't want to just say "let's give up on her, she's just going to deteriorate and die." Even if that was and ended up being the case, I still wanted to give her the best, everything that I could, but what did she need? And besides the basic needs, nutrition, hygiene, mobilization, what was her need? And for me, my patients are just like me. I walk into their room and they want what I want. They want to be happy, they want to be respected, they want to be affirmed, they want to be told that "you matter", you know, you have value not because of what you are able to do and most of my patients really can't do much. They don't really serve society, they aren't productive in the way, they don't work, most of them. But they have so much value. And so I wanted, looking at her, what killed me, what really was really killing me, was that I wanted her to know somehow that she mattered. And I didn't know how to communicate to her. I really didn't have any answers and I was just going day by day, and then all of a sudden, a thought came into my mind, you know "if only we could talk to her in her native language". Because she was really never fluent in English. So basically I just came up with an idea, I just thought "what if I get someone who speaks Russian and who could just come and talk to her. She won't talk back, but at least, like to say to her "it's okay. How are things? And just let her know you're alive, we know you're alive and we care about you." And so I made a strange request to the interpreting service and I asked that the interpreter would come although he wasn't going to have to interpret anything. He was just going to talk to her. I thought she would feel alive and valued. The director of the limited English proficiency program really told me "You know this is really not kosher. We don't do this usually." But I'll try. I'll give it a shot because you know it seems like maybe it's good for this patient, she needs that. And when he came up that day, her eyes were open. She was just staring and he started talking to her and very soon realized that she could understand us and she could blink when she wanted to say yes. So we started basically having conversations

with her. We would ask her if she was in pain, you know and then we just started off asking “What can we do for you?”. And we would ask her “Are you in pain?” “No.” “Do you want us to play music?” “No.” “Do you want us to read something?” “Yes.” She wanted a specific religious book read to her. So the interpreter started coming, reading and spending time with Katia. Every day at 2pm, he would be there. He would sit on a chair next to her and start to read for an hour or so. Weeks went by and she continued to respond, everyday a little more. One day I found her smiling at her children in her bed. They had come to visit her, and when I walk by, even if she wasn’t in my assignment, I would walk by her room and see how she was doing and hopefully catch her husband, talk to him a little bit. I would, and if I saw the interpreter, you know, reading to her books or whatever, or just talking to her, it just filled me with joy because I knew I wasn’t curing her. She couldn’t be cured. But that we were not just letting her die in her bed and I knew that she wasn’t alone during those hard times. And unfortunately after improving a little bit, she declined irreversibly and she passed away last year.

So, the second case that I want to talk to you about is of a middle aged woman, Ms D., with a history of back injury. It’s really kind of sad because it was a surgery that went bad and she was left with abscesses that needed to be drained but there were several of them. She was in extreme pain. She couldn’t really ambulate anymore and in report I was told she’s depressed. So going to her room, and I met her and she was sad. Her face was very sad and she was actually angry. She was bitter. She could not move, she couldn’t really, and she was never pain free. She was in constant pain and then she’d get pain medication and her mental status would be not really good. She would become really sleepy. And I felt her pain and sadness. And so she was really desperate. She did not have any hope of ever getting better. And it was so hard for me to face her despair. That was the hardest thing. That she didn’t see any hope. And so I tried, I would go in the morning and introduce myself you know, and just say “hi. I’m going to be your nurse today” and ask her what she needed and listen to her. And oftentimes, she’d talk about for 20 minutes and about how angry she was or sad she was. And I just listened because I couldn’t really do much for her. I couldn’t fix her. I couldn’t do surgery. And I just really wanted to find out a way to help her. And when I addressed it with the doctors, they just said you know “She’s depressed. We’ll just increase her antidepressant medication” which she needed undoubtedly. I’m not criticizing that but... Something happened between me and Ms. D. And it was the fact that every day, I would go in and just look at her in the face and really actually listen to her. And so when we had multidisciplinary rounds, they would come in and ask her “how are you?” and they kind of never gave her time to finish because she would go on about how you know her bitterness. And she was irritated because there were about 15 people in her room they really weren’t talking to her, and they were just like looking at her body and so, they wanted to know about her case and that really made her angry. She was very annoyed and she pretty much stopped answering the attending’s question when she’d come in and so she’d just leave. I just thought “what can I do?” The psychiatrist came and increased the dose of antidepressants and I would go in and talk to her and ask her “how are you?” And then again I would basically just listen to her, give her pain medication and I wouldn’t do any really amazing thing. But I understood that a big point, that one of her main problems was that she had lost all her trust in doctors because they made a mistake and, after making a mistake, her surgeon wouldn’t really come in and confront her about it, which was not really professional, and not very human, but I couldn’t fix that. I couldn’t really say that something specific happened, but it’s like the case of a long-term friendship, you can’t really pinpoint what happened. But then for over a month I was her nurse, in and out of the room,

and just doing my nursing job. She was a woman confined to her bed. It was hard for her to accept her situation. But through this and because of this, we built a relationship. She knew I cared about her so when the whole team would come into the room, pretty soon she'd just scream, and go face by face and when she saw my face, she just smiled and just talked to me only in the whole room. You know, one day, I went to her room and I saw her hair was all pulled up in a ponytail and it was really dirty. It was super oily, she had been there for so long. We don't have shampoos. I don't know about other hospitals but we don't because patients are supposed to stay there for a short time. So she really needed a shampoo and I got her sister to buy her some. And the one day, I washed her hair. And honestly that's not the kind of stuff I like to do, it's not like I go around giving people baths. I really don't have time for that. But I knew that for her that was huge. I mean, for a woman to have really dirty hair, it just kind of diminishes your dignity. And so I just washed her hair and her hair was so clean and she was so happy. And she was first mad at me because she said I was doing too much for her and I was like 9 months pregnant, but I was so happy to do something for her that was so small and she said to me "You're going to deliver the baby in the room now!" she was really scared. She didn't want me to pull, lift, do anything, but I just did it. And basically, what I think happened is that she saw that I didn't care about her case. For me, she was a person, it's like a friend. Meaning, not that she's not my friend, she's my patient. But I was interested in her, in who she was and so I cared about her. I realized that if you don't care about the identity of the person, patients see that. They know that even if you're very professional and you do things right, they know you don't really care about them. And so for her, it was not the same. With me, she really had a preference and a really particular relationship. So these are two cases and over the years, over these three years working as a nurse, there have been hundreds of encounters that have left really a mark on me. I mean I could like write a book. There are many moments with patients that have reminded me of why I'm a nurse. When I forget who the person in front of me is, that's when I can't tolerate the system any longer. I mean, we'll talk about it later about health care reform. I mean, health care is not really good and the situation is not good. And yet, what saves the day, what makes it worth for me to go to work are these stories. Ms. D and Katia, and all the people that I've met. And so, for me, the only way to adequately take care of people is to treat each of them as an individual, as their own person, not as the patient. And so when I look at them, and I really ask them "what do you need?" That's when I can develop a plan that's individualized and it works better honestly. You know like, in the case of Katia, I could have never even thought of something like that. And so, by caring for these people, I discovered them, they're just like me. Because at the heart of the matter of the medical profession, there is just a person, like I am. They want to live, they want to be meaningful, they want to be loveable, and they want to have someone care for them. Often, disease seems to take away the very thing that made them loveable. We know what makes people feel important. And this happens because society indoctrinates us to believe that a person's value is the outcome of his or her actions. So when you're sick and helpless, incontinent and sad, society tells you "You have no value or importance". Instead, every patient is a desire and in desperate need for another to enter into their room to tell them that they're great. That very desire is great. So even depression, anger, suicidal ideation, they're all alike, just come out of this desire to be happy and they just can't. They don't know how to cope with it. Patients don't know what to do with it. So for me it's a privilege to accompany each person and to serve them in that very need, in the very need that's a huge need and every little need that they are constituted at all. And I'd like to add that throughout these years, I discovered that nurses aren't like the compassionate ones and the doctors are not, it's not

like that. I can become used to pain and suffering. After a while, you just don't react the same way. It doesn't hurt you anymore or not as much. And soon enough you just become 'that's how it goes'. And you just become used to pain. And so for me, the point isn't to take like holistic or ethics courses; it is very important to know about ethics but what has happened to me has just been possible because friends have sustained me in following my purpose; my initial idea for why I became a nurse. Because after a while, for me the system makes me so angry just what we have to comply to the standards, to the charting, the wasted time that I really can't spend with my patients. Really it would just suck me in and I would leave. Instead I stay and people ask me "How's your job going?" and I say "Terrible" but then I say "Wonderful" because it's great because of all these people that I've met and I've had really the honor to serve and so, thank you.

**Ginny Darling, RN:** Hi, my name is Ginny Darling and I'm a nurse in neonatology and obstetrics. I work at the Mayo Clinic in Rochester. I've been there for 28 years and I've worked in a lot of different areas. I'd like to thank Elvira who asked me to come here after a brief conversation that we had. And, Elvira and Elena have put a lot of work into this. I would like to thank them for all they've done. I went into nursing because I wanted to be with people on a real level, and I consider it a privilege to be able to do that. Where else could you walk into a room, someone would tell you their secrets, they would disrobe, they would do what you ask them? You don't do that at Penny's. So for me that's a privilege to be able to do. This particular case happened several years ago. These were first time parents, who were pregnant, and their midwife suspected she had twins. So they did an ultrasound and found conjoined twins. They came to our tertiary medical center, and we did another ultrasound and they found that they were joined at the chest. They were unable to separate them surgically. So, their length of survival wasn't known. We didn't know if they would live for hours or days or what would happen. So a plan was made with the family and the physicians about what to do. And they decided to deliver the babies a little early, and plan for comfort care in the hospital, which is what you had talked about Debbie. Comfort, hydration, eating, pain relief, and anything to keep them comfortable. The day they were born, they did well. They were breathing, they didn't need oxygen, they were stable. Everyone was delighted especially the parents of course. Then they were hungry, which was a surprise as well. They showed sucking behavior like they wanted to eat, so we fed them. We bottle fed them and they didn't really have enough energy because of their prematurity and because of fatigue to really eat enough to sustain themselves. So we placed an oral gastric tube from the mouth to the stomach and fed them formula. The mother wanted to breast feed but she wasn't able to because the babies were essentially facing each other in an embrace and it's hard to breastfeed them. Fairly soon after that, the parents expressed a desire to take the babies home and care of them themselves. So this was new for us. Where I work is an intermediate special care nursery. Debbie works in an NICU for the sickest babies. This is an intermediate nursery where babies are not that sick, they don't need life support but they need to feed and grow. So most of our babies aren't sick. So this was a different scenario for us and we said "well, ok." We thought about it and planned it with it. But to the parents, the babies were a beautiful gift. That's how they saw them. Their babies. And before we did, they really accepted the reality of the situation. That they wouldn't live long, and that they would need a lot of care. So we taught them everything they needed to know: how to place the tubes, how to measure them, how to give the feedings, how to do all of those things. The father made a wooden frame to put the syringe full of formula on, and we experimented with different heights, so that it would run in slowly over 30 minutes because it's a long time to hold two syringes for 30 minutes, every three hours. It's

really not possible. So it was very simple and inventive but it worked really well. It was good teamwork. So for these parents, the way they found meaning in their babies' short lives, was the love that they had as parents and the opportunity to be parents. Sometimes, there's such a separation when the baby is ill or when they can't go home that it's hard to be a parent, it's harder to believe that you are. And this was a great joy to them to be able to be parents. To take them home, to do those things they had always dreamed of doing. It included sharing the babies' cares and joy with their community and their extended family. They had a good and supportive community and that was the main reason they were able to do what they did. And their faith in God which was inspiring to us. It wasn't unusual, but their courage in the face of this was, we thought, remarkable. The babies lived for several months. They had followed care at home with a physician and a public health nurse and we would receive letters, and we got excited and well babies are eating this much and they gained this much weight and what was happening. And one day, we got the letter that they had died very peacefully at home, and their letters were so peaceful. This is what's happening in our day, this is what's going on. They were more peaceful than we were I think. Like I said, hospice care was in no experience for us as nurses. What we ended up doing was listening to parents and following them and the reality of the situation. They taught us. Their desire became a provocation for us to follow them on their journey to the destiny that their babies had. It did take a lot of creative care and teamwork. There's a state law in Minnesota about car seats and we found a car bed that lays down in the back seat, and we were able to put the babies backwards and fit them in there. That's the only way we could do it. So there were a lot of things. We also accomplished this over a weekend, which for those of you who work in a hospital, the big people aren't there on the weekend they were able to go home on a Sunday, which seems small but hospital care is expensive and it was good work. We appreciated it. Our role wasn't as a sole caregiver, which often happens. We are taking care of your baby and we will tell you what to do. We became a bridge for them to meet the needs that they had. So in conclusion, we learned that there is more. There's more beauty. They were beautiful babies and that's how their parents saw them. There's more to nursing care than our routine and what we already know, and what's already safe. And there's more to each of our humanity because what happened affected them, affected us, and we were all changed by that. The letters we received opened our eyes to another way to living and dying. And personally, I am very grateful to them for sharing this time in their lives with us. Thank you.