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Alfred Steinschneider

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Alfred Steinschneider

“SIDS: current areas of interest: apnea, monitors, and the high-risk infant”

October 20, 1979

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HOST: Our speaker for the afternoon is Doctor Alfred Steinschneider, whom many of you met this morning. Doctor Steinschneider [*baby crying in background*] comes to us from Baltimore, where he is professor of pediatrics at the University of Maryland. He has about an eight-to-ten-page CV, which I'm not about to run through... [*baby yelling*] except just to say he's been to all the right places, he's done all the right things, and he's written a lot of very impressive articles, many of which relate directly or indirectly to SIDS. He currently directs the largest federally-funded research effort into SIDS ever funded, and well he should, because of his background. He began working in the area of SIDS, I believe, about ten years ago, when they originally defined sleep apnea and noticed that some of these babies wound up in the local medical examiner's office. I believe that was a series of five cases, but at least it was a definitive word that started everybody thinking.

I divide the SIDS area, I think, into two problems: the human problem and the scientific problem. The human problem, of course, is what can we do after the death occurs? We heard a little bit about that this morning, what we can do with the parents; how we can make them understand what happened to their baby. And a lot of dramatic improvement in this area in the last seven to eight years. A lot of people have been responsible for this. Dr. Abraham Bergman, whom many of you probably know. I think Abe is primarily a politician who happened to go through a medical school of pediatrics residency, but that's what we needed back then. Through the efforts of Abe and the Goldbergs—and I like to think that we played a part—had a

significant input in the early 1970's into upgrading the management, the diagnosis of SIDS, and the problems that followed with the parents thereafter.

This has continued. We could go through state by state and develop a perfect medical examiner system. We could develop a perfect system for follow-up with public health nurses. We could have adequate and dedicated input for parents' groups in every state in the Union; that's not enough. Why? Because the babies are still gonna die. Brings us to the other side of the question and that is the scientific side. How do we identify a child at risk? How do we figure out which baby might wind up in the office and which does not? How do we predict it, if we can? And how do we prevent it? Dr. Steinschneider, I think, is the single individual who has had the largest input into the scientific investigation inquiry into the causes of this disease. From his efforts and his original work, a lot has flowed. There are some very good programs now. Dr. Shannon in Boston, Dr. Dement who's down at Stanford, people in Seattle, and Dr. John Yount with the University of Oregon (hopefully). These people have built and enlarged upon Dr. Steinschneider's work; but I give to you now, the individual that I think really started it all.

[*applause*]

ALFRED STEINSCHNEIDER: I won't be able to yell, so I'm going to use the microphone. Thank you very much. I assume you can all hear me. I'm going to take issue with you, but you knew I was going to do that.

HOST: Oh, I knew.

AS: You were waiting. I hope to be considered a scientist as opposed to a humanist. I don't view myself as a scientist. I view myself as a concerned potential grandparent, and I'm trying to go about the business of becoming a grandfather. Okay? To make it extremely personal, a number of years ago, my daughter laid on me a problem—she, now, is 18, she damn well better not be pregnant [*laughter from the audience*]*—but she said she's not [going to have a baby] until this particular problem that she's heard a great deal about is pretty close to a solution. Now, I want to be a grandfather. Don't ask me why; I do. And it just seems to me that if I want to be a grandfather—and one of the ways to do that is through my daughter—this problem is going to have to go a long way to get solved, and that's a very human problem. Not only that, but when one talks about *the* ultimate, if you will, humanistic way to deal with the problem, it's to deal and prevent the death.*

Sometimes we get confused. Sometimes we lose perspective. And sometimes we lose perspective because of where we're at a particular moment in history. The trouble with that is

that we tend to get locked into particular points in history, and it takes us a long time to get out of it. There is no doubt that at one point in time the only way to go... no, sorry, one of the major ways to go was to be concerned about the parents who lost the baby to SIDS. But if one carefully looks at history, you find that those who went to work when most of us were just thinking about SIDS, dealt with more than just—and I really shouldn't say "just"—what happens after the baby dies; after the problem. They went to work and tried to get a process initiated which has gotten us to where we are now. You will hear from the Goldbergs [Saul and Sylvia Goldberg], who are co-founders of the Guild for Infant Survival. You know about some of the activities of the National SIDS Foundation. These are concerned people who, yes, were concerned about the impact, but also initiated a process which had as its primary goal the prevention of death, and we sometimes lose sight of that.

Now, that may not have been the major effort, the major visible effort, but I'm... what I'd like to throw out at you is that that effort is beginning to pay off. Now, let me make another brilliant statement. The problem of SIDS is not the problem of the scientific community. It is not the problem of the medical community. It is our problem. It is our collective problem. What I, as a researcher, can do/cannot do depends, in large part upon what you want me to do. 20 years ago, 10 years ago, the particular study that we are now doing in Baltimore could not have been done. You didn't allow it. Because of the efforts of the Guild for Infants... concerned parents! I don't wanna keep saying, "the Goldbergs," because it was more than the Goldbergs! It was concerned people! Because of what they did, they made it possible, now, for a fairly extensive program to take place, a research program in Baltimore. So in a very real sense, whatever results, whatever good comes of it, comes of it because we—collectively we—wanted it to come of it. It comes about because we care about our infants.

Now, for good or bad, you're capable of reading, and I mentioned earlier that one of the mistakes we've made, possibly, is that we're teaching people how to read. Now, one of the offshoots of people reading is that they know what's going on behind the usually closed doors—the laboratories—what's going on in the scientific community. Unfortunately, much of what goes on and is translated, transmitted, to the public at large is poorly understood. And it's poorly understood because the concepts aren't there. And I'm afraid that if you are going to participate in this overall activity of helping to get this problem solved, you're going to have to share collectively with us some of the uncertainties, some of the confusions, and some of the sophistication, if you will, that's going on in rather tight laboratories. Some of the debate that's going on, disagreement that goes on in cloistered halls. You hear about it, but you hear about it in very awkward ways; ways that make no sense. If you... so I think it's appropriate that we begin to talk about them. Not only that, but it wasn't too many years ago when those of us learned individuals who are orchestrating SIDS... many of us sort of felt that you all couldn't

understand what we were doing or talking about, and you had to be protected. And so, much of what you were told, or at least some of what you were told, was not even true at the time you were told. It's about time we all began to talk from a common base of knowledge. What do we know? What don't we know? Okay? And what I'm suggesting is it's about time that people in the medical community, people in the scientific community, stop handing out pabulum. The community wants to know, people want to know, what we're talking about, what it means. They're raising questions, why? Because you can read. The press was here. They're here, not because I photograph that well, they're here because they think it's good press copy. People want to know about it. So the public wants to know, so let's talk about some of the mystique, some of the concepts, some of the things that are coming down. Some of it may sound mundane, some of it may sound semantic, but believe me it's not.

Let me start with the blue book, okay? Because I want to show you what can be wrong, and what we knew what was wrong at the time we wrote it. All right? If you look at the first page, count the number of dots, the number of blue dots. There are, by my count with my bifocals, there are 9 blue dots. I object to five of them. And I objected to five of them at the time the nine were written. Let me tell you the ones that I think we can say... the ones I disagree with, eh? One, SIDS is a definite disease: pure nonsense. Unadulterated, unequivocal nonsense. It is not a definite disease. Death is always definite, and to talk about *death* as being a disease confuses me.

And while we're at it, let's... can we have the first slide? Let's define SIDS. And this may take issue with... [*chuckles*] a previous speaker, but I think *this* definition was the first major breakthrough in the area of unraveling the mysteries of SIDS. It was a definition that was proposed in 1969, at a conference, all right? And it was proposed by Dr. Beckwith, and there was a lot of discussion and there was a consensus. Now, let's read it, and here is a definition: "SIDS is the sudden death of any infant or young child which is unexpected by history and in which a thorough post-mortem examination fails to demonstrate an adequate cause of death." Is that a definition of a disease? Is that the definition of anything distinctive?

I look at that very carefully and what I find is that it's a statement of ignorance. What it says... and *that* was the breakthrough. It was an honest statement by a group of people who said, "These babies who look healthy die, and we don't know why they're dying. What do we call it? Let's call it SIDS." Fine. But we don't know why they're dying, and *that* was one of *the* first major breakthroughs; it was a statement of ignorance. It was not... they were not saying, "These were babies who were dying of pneumonia," or "We could fake out a reason"; they were saying, "Let's face it. Let's call it the way it is. We don't know why they're dying." So there's nothing distinctive about it; it's death.

Not only that, but it leaves... if we recognize what it says, that we don't know why these babies are dying, it avoids a lot of debate about whether or not it's a syndrome, or whether it's a disease, or whether it's one disease. It avoids the debate that goes on that I hear all the time: "Gee whiz, Al. You believe that apnea causes SIDS, right?"

"I do that."

"Then how do you handle the possibility that botulism could be responsible for SIDS? Do you believe botulism could cause SIDS?"

And I said, "Sure, I believe botulism can."

"Well, how can you believe botulism can and apnea can?"

Because I believe a whole slew of 'em can! If I don't know what the cause is, there's no logical reason to assume there *is* a cause.

Okay. A whole lot of debate disappears. Of course there are multiple causes! And that has very serious implications. It really means that even though there are a few of us who think that the apnea theory that we'll go into is right on, because we're saying that there are multiple causes—probably, just on logical ground—it means we ought not to cut off all other avenues of exploration! Other serious hypotheses have got to be explored! Must! Because if you account for all that apnea can account for, and that represents 72.8% of SIDS deaths—I made up the number—there are still, what? 27.2%? I don't want that 27.2% to be my grandchild.

So *all* of them have to be prevented. So we leave all our options open and we leave it open because it's in the diag... the definition that says don't close them off. And so a lot of debate that went on... strange as it may seem, a lot of wasted energy went on talking because people didn't know what the definition was. Question comes up: can a baby die of SIDS after three years of age? Of course they can. What more does that mean? It means can a baby, a young child, die, unexpected by history and which remains... in which a thorough postmortem examination fails to demonstrate an adequate cause of death. Can that happen in a 3-year-old? Of course it can! Why can't it happen? Why can't it happen in a 4-year-old? And 5? In a 30-year-old? In a 40-year-old? Do we always know the cause of death following a post-mortem examination of an individual who was apparently healthy and then suddenly dies? Of course not. If we say we don't always know, then we have the potential for learning. If we say we know and fake ourselves out, there ain't no potential. We've closed off our options, and indirectly are

responsible for the continuance of the deaths. That's number one. We'll keep the definition up there.

SIDS cannot be predicted or prevented, even by a physician. [*pretends to ponder*] Hm, hm, hm. We already talked about that. That was so unnecessary. I don't know why it was put in there. I think the reason it was put in there was because we were trying to deal with parents. We were trying to make parents believe that there really wasn't anything they could've done. That they did a... that there was nothing they did do, or nothing they didn't do that was responsible. Well, why don't we just say that? Why don't we say to parents, "Look, I don't know why your baby died, and I don't know what you could have done or what you didn't do that could be responsible." In fact, if somebody in this audience could tell me what we're doing [that is] responsible for the deaths, then I can prevent them. I wish to God I knew what we were doing—if there was anything we are doing—to our babies to be responsible for deaths, because if we knew, we'd stop it! The point is at this particular moment in time, we know of nothing that we are doing or not doing. Hopefully, in the very near future, we will know. And when we know, we'll stop and our babies will live.

All right? So this business about predicting or preventing—you're darn right it's gonna be predicted; you're darn right it's gonna be prevented. If I felt it could not be, I wouldn't've spent 10 years of my life and I'd give up the notion of being a grandfather. I keep coming back to that. I want to be a grandfather so bad I could taste it. [*laughter*] Okay. 3 and 4 are by. Let's take one that I know is gonna be painful, okay? I know it's gonna be painful, especially for those who've lost a baby to SIDS. It says there is no suffering. I don't know that that's not true. I don't know that. I don't know what happens during the terminal event, and I don't know how the hell we're going to know. We do know this: that if the baby suffered, it certainly didn't take a long period of time. In fact, there are theories that imply that the baby may have suffered. If we buy the theory proposed by Dr. Beckwith that there is airway obstruction and that the airway closed, and the baby tried, struggled to breathe against the closed airway. If that's not suffering, I don't know what it is. But it's brief. There's no point in that; the baby died, and it was very brief. I can't accept that, because I can't say that that's true. I can't say it's not true. So why say it? Let's face it honestly. We don't know what happens when the baby dies.

Okay, let's go on. SIDS is not hereditary. That... this is now where we get to mumbo jumbo, okay? We say it's not hereditary. Really, parents don't want to know whether or not it's hereditary. Parents want to know if it's more apt to recur. Now, what most people don't know is that familial recurrence is not the same as genetic... so we faked them out. Okay? They really are asking one question, we answer another. And we say, "Yep, it's probably not genetic." And it probably isn't, but does it recur? Yep. There is an increased recurrence rate. Is it horrendously

high? Should it interfere with having other babies? That's a decision *each* parent must face. I can't make that decision for a parent who's lost a baby whether they should or should not have other babies; *they* do. All I can do is tell you what the facts are. The facts are that if you've lost a baby to SIDS, there is an increased likelihood that a subsequent child is going to die, and that increased likelihood rate that you've heard was about five times greater. So if the rate—let's make life easy—normally is around three per thousand, two per thousand—let's say two per thousand, makes it easier—then five times that is 1% in a family that's previously lost a baby. What does that mean? It means that 99% won't die—subsequent siblings won't die—but one percent will. Is that risk too heavy for families who have previously lost a baby? How do I know? That's an individual decision people have to make. What I'm responsible for is to give you the facts as we know them. Those are the facts; you decide. What we did here is, we tried to make the decision for them, and in this particular brochure... in other brochures it usually stops with the heredity part. In this one, we went full blast! "There is no greater chance for it to recur in one family than in another." That's downright untrue. That was untrue when it was written.

Okay. All right, the last comment I'm gonna make about SIDS: that it's at least as old as the Old Testament—it is not! Absolutely not. Now, I've said that it is. I've gotten up in front of a group of people... and I always loved to tell the story about Solomon. Remember Solomon? Those of you who saw Cecil B... I get my Bible out of Cecil B. DeMille. And remember Solomon and the two mothers who claimed one baby? Okay, the baby that died, died suddenly and unexpectedly, but is that a SIDS? Well, let's look.

"SIDS is the sudden death of any infant or young child which is unexpected by history." Well, that's true. That baby's death was unexpected by history. "And in which a thorough post-mortem examination fails to demonstrate an adequate cause of death." Did the baby have an autopsy? Ask Dr. Lumin. [*laughter*] That baby did not have a thorough post-mortem examination and therefore the baby died suddenly and unexpectedly, cause unknown. Could it be? When I say cause, it could very well have been an identifiable cause, had the post been done. But it wasn't! So we don't know, and you can't call it a SIDS. So when we're trying to fake ourselves out and are saying, "It's always been with us," it's been with us as long as competent pathologist medical examiners have been doing their job. That's as far back as we know it goes. Whether it goes back beyond that is probably true, but if you want to argue that it ain't true, then at that point, the debate ceases... 'cause there's no way to find out, so there's no point talking about it. All right? So there's a lot of mistakes.

Now, we've looked at the definition of SIDS; let's take a look at some other definitions because you know, strange as it may seem, the place where we run into trouble—most of our trouble—is due to lack of clarity in thought. It's difficulty in identifying the problem. In fact, the biggest

problem that we're gonna have in solving this thing is coming up with the right questions. Now, most research and thinking is to try to find out a key... the right question. Sometimes what makes it difficult is confusing concepts. Concepts that come from here, and stay there, and end there, and finally end up giving you heartburn. They kill ya.

Let's talk about one such concept, and you're going to hear more and more about it. It's the concept of the aborted SIDS... okay? It was brought up earlier. To me the concept is totally without foundation. It is an emotional term. This is not to say that there are not babies... [pauses] [softly, to someone] Yeah. [pauses to adjust microphone] Like so? I'll try it this way. Is that better? Okay. [resumes] The concept of aborted SIDS, a near miss, came about in 1965. '65? '65, yeah. And it came out as a result of a brilliant insight. You see, now, people were sitting around talking as if once the whatever the mechanism, in regard to SIDS, once it hit, that's it. Forget it. You've had it. The baby was gonna die. All right? In fact, one even reads today in some of the brochures that even if the baby was dying and a physician was there, they couldn't have done anything about it. How they would know that—anybody would know that—is beyond me, but... Dr. Guntheroth, who doesn't live far from here, had a brilliant insight! He said, "You know, isn't it possible that there are babies who are found in extremis, apneic, cyanotic, pale, limp, and who are resuscitated? If no... isn't it possible that if no one was there, that these babies would have died? And following the post, the diagnosis would have been SIDS. Isn't that possible?" Because if it's possible, then what we're really saying is that this is a resuscitatable disease... problem. Not only that, but it also gives us a group of babies—if this is true—that we can study intensively to give us some clues as to what almost did them in. And then, during the conference, people sorta got intrigued by the idea, and some person began referring to it as the near-missing or... and all the sudden there is a "near-miss" concept, and it came out again in the next conference; and all of a sudden now, it's the key phrase.

There are two key issues in terms of the meaning of that particular term. First of all, let me just tell you what I think about a term like that, and part of this is semantics, all right? The term "aborted SIDS" is something Woody Allen would play with... because let's take a look at it. First of all, to talk about SIDS requires death and requires a post-mortem examination. It requires that Dr. Lumin did his job, right? Now, how do you go about getting an aborted... dead baby who's had an autopsy, who's alive? I don't understand it. What isn't... so from the point of view of terminology, I don't understand. Certainly, it captures onto the emotionality of the concept of SIDS. What's really being said is that there are two concerns. One, if someone had not resuscitated that baby, the baby would have died. Well, let me submit that since we will never know the answer to the question of what would have happened if nobody had resuscitated that baby, it's a moot point, because if we had a baby right here on that table who suddenly stopped breathing, turned blue, and got limp, we would not be sitting and watching to see if that baby

spontaneously recovered. Somebody couldn't handle it and would get up and resuscitate that baby; wouldn't you? You couldn't sit and watch that baby, and no one could. Nobody's gonna do the kind of study to find out whether or not that baby—as a group—would have spontaneously recovered.

I'm going to show you a slide later on of a baby who was a near-miss. As far as my nurse was concerned, she was sure the baby was going to die, but the baby fooled her. Without any help from anybody, she started to breathe on her own—the baby started to breathe on her own—which means, it's tough enough making the diagnosis of *death*. It's impossible to make the diagnosis of *dying*. All right, so that's a moot point whether they would or would not. The other is that these are babies who are at an increased risk *to* die. That if you took a hundred such babies who've had these episodes that—and followed them, did absolutely nothing and followed them—that a large percentage of these babies will subsequently die and die of S-I-D-S. Unfortunately, there's been no systematic study like that. Number one and number two, it's unlikely that such a study is ever going to be done. Why? Because if a baby comes into the emergency room after having been resuscitated, it is the medical/legal/ethical obligation of the clinician to intervene. From there on in, you don't know what the natural course of that problem is gonna be, so we'll never know. It's part of the fact that I'm saying: let's dump the term because it's more emotionally loaded. And, by the way, I've heard parents who screamed up a storm every time the house staff passed their living baby and said, "Oh, in there is the aborted crib death." And they would scream up, "But my baby's alive!" All right? I think we would do well to call it what it is.

If a baby stopped breathing while asleep, then let's say, "This is a baby who had apnea while asleep." If the baby stopped breathing while being fed, then let's call it that the baby stopped breathing while being fed. I've had babies referred to me for diagnostic evaluation—referred to me as aborted SIDS—who had perfectly benign problems. Some of these babies had crying breath-holding spells. Some of these babies would cough, they would—some had whooping cough—would cough and suddenly turn red... and this frightened the parents, frightened the doctor, and they'd come in and they were aborted SIDS. In other words, if we keep using the term and not start categorizing these, the term itself is gonna drown us, and I make the point because we're already in the process of being drowned by that term. Research is being done on that concept and it's very confusing. And it's very confusing because none of us know what the other is talking about... but we think we do, but we really don't.

Okay, that's the... but don't misunderstand me! What I am saying is that these babies who have these episodes are babies we ought to be concerned about, because I do believe that these babies are at increased risk to suddenly die. Some of these babies, not all of them. I don't like

the term. I think we have to stop. As long as you hear the term, I think we're gonna find ourselves in terrible confusion and until we start learning not to use it we're gonna keep being in trouble.

Let's talk about the word apnea. You think apnea would be very simple. If you look it up in a dictionary, what does it mean? It means the cessation of breathing. But how is it used? It's used to mean two things. It's used to mean the cessation of breathing, yes, but it's also meant to mean inability to breathe, okay? So in the one case, with the cessation of breathing, we talk about it as diaphragmatic apnea, that is, where the diaphragm doesn't move; some refer to it as central apnea. In the case where there is an inability to breathe, inability in a sense that the baby is *trying* to breathe but there's some obstruction. Where? Who knows. But something is occluding the airway, it's referred to as obstructive apnea. Both of these do and can occur in infants; they do and can occur in adults. But there's another issue, and one that you're going to get confused about, 'cause I'm confused about it. It has to do with the duration. How long must you not breathe before you call it "not breathing"? How long is long? Did that question come up earlier? [*inaudible response from the audience*] Well, it very often does. How long is long? How long can you not breathe? How long do you want a person not to breathe before you say it's pathologic? Well, it turns out that it's very unlikely for a baby to stop breathing for periods in excess of 15 seconds; studies have been done. And so it is by consensus agreed that pathologic apnea is apnea that's at least 20 seconds in duration. Furthermore, we will consider pathologic apnea to be that period of apnea, regardless of duration, associated with a color change; a baby turns blue or pale, or there's a significant drop in the heart rate. So these are all considered pathologic.

All right. Now, what about the monitor? This, I find, is a beaut. Whenever you talk about monitors, it's the most amazing thing. I've seen more comments written about monitors, about poor little old electronic gadgets who can't talk back, than you can shake a stick at. Now, what do we mean by a monitor? A monitor is nothing more than a sensing device. That's all it is. It's something that provides some sort of surveillance. It's a gadget, usually. Now, that gadget—there's nothing implied in calling something a monitor that tells you what it monitors. I could have a monitor that measures the humidity in this room, the temperature, the amount of carbon dioxide, the amount of oxygen, et cetera, et cetera, et cetera, et cetera. I could put a monitor on a baby that will measure temperature continuously. I could put one on that constantly records blood pressure, heart rate, respiration, the amount of sweat... okay? So to say that a baby was on a monitor is not enough. You got to say what kind, because if the problem you are monitoring is one in which the baby you're concerned about an event: the baby stops breathing. And I put on the baby a thermometer, under the skin, eventually that thermometer is going to scream up a storm because the baby's temperature's gonna drop very

low. If you run into the baby at that point in time, you will find the baby dead. There's nothing wrong with the machine. The machine did exactly what it was supposed to do: it sounded an alarm when the baby's temperature dropped below a certain value. What was the problem? The problem was the doctor put the baby on the wrong kind of equipment! All right? When we hear about babies dying on monitors, one has to ask the question: was the baby on the right kind of equipment? You can't blame the equipment if it does its job.

Now, what else about... what else has this equipment been accused of? The equipment has been accused of not saving a baby. Well, it never was designed to save a baby; it was designed to alarm, that's all. Most of these machines were designed by the electronic engineers to do this: beep beep beep beep beep. That's all. It doesn't get up. It doesn't pick the baby up. It doesn't give it mouth-to-mouth. It doesn't do anything. It just goes beep beep beep beep beep, and it's part of a system requiring that somebody respond. If a baby is put on a monitor in a hospital, and the nursing station is here and the baby is put in a room down at that end, with a nurse over here, and that baby is found dead with the monitor going beep beep beep... the accusation has been made that the baby died on a monitor. Of course the baby died on a monitor. The baby was provided inadequate care! Somebody was supposed to respond, and it was the response that broke down; and that's very serious, because if a baby goes home on a monitor, you have to have somebody capable of responding and responding rapidly, and in a method that is adequate to the baby's needs. So if you have somebody who doesn't know how to provide CPR [*chuckles*]... [*serious tone*] you're in trouble. It isn't the monitor, it's poor care. What I'm getting at is the monitor is nothing more than a gadget that's part of an overall care package. When you hear the criticism of the monitor, most of that, as far as I'm concerned, is defensive. Somehow the system broke down and part of the system that broke down could have been a judgement on the part of the physician. It could have been that the rest of the support system—the responsive system—was inadequate to the job... okay?

Now, for time purposes, we're not gonna go over all the criticisms of the monitors, but what I am going to say is whether we like it or not, monitors are here to stay. And the reason monitors are here to stay is because the problem we've got is one of continual surveillance. When a baby has a severe recurrent episode like apnea, and we cannot turn these episodes off—wave a magic potion over the baby so that it goes away—the problem we've got is to at least be aware whenever these episodes occur, so that we can resuscitate the baby. Now, the problem, then, reduces itself to something very simple. If you've got a baby who has these episodes—when I say “you,” I—as a clinician, am taking care of a baby, I can do one of two things: I can either watch the baby in a hospital or I can watch him at home. If I watch him in a hospital, I'm gonna be watching that baby for upwards of six to seven months. And how am I gonna watch the baby? I can watch the baby one of two ways in the hospital: I can have a person sit, watching

the baby, or I can take advantage of modern electronics and have a piece of equipment watch the baby, in part. What will I do? If I kept the baby in the hospital, I'd attach the baby to a monitor for six to seven months. Compare that cost and psychological trauma to the parents and the baby, as opposed to the baby going home, on a monitor... all right?

Now, there's no doubt, it's not easy taking care of that baby, because the parents are being required to take care of the baby 24 hours a day, 7 days a week; and it's not easy. The alternative we're faced with at this particular moment in time is not between good and evil, but between various shades of evil. They're both lousy things to have to do: keep the baby in the hospital for an extended period of time, or keep the baby home on a monitor. The problem, then, is which of these two is the lesser of the evils? Which produces the least amount of harm to the family and to the baby? I would submit that in most instances, putting the baby on a monitor at home, in general, is less traumatic than keeping the baby in a hospital for an extended period of time. In fact, I think, honestly, that the baby will get so much superior care at home that there's no comparison. No nurse—with all due respect to the nursing profession—has the time, okay, to provide the kind of stimulation and love and ongoing kind of development... the ongoing kind of relationship that parents can. So I think when put on a scale, you're better off at home.

But it poses problems for the parents. And part of the problems are equipment problems... okay? But before we get to that, one of the things inherent in the equipment... let's take a look at a couple of slides. Let me see if I can snow you a bit. Okay, I talked earlier—before we get to the actual equipment—I talked earlier about the kinds of obstruction and apnea that can develop. You'll hear a great deal about sleep apnea, okay? All right. And now, let me tell you what I believe... okay? Which borders on a religious statement. I believe that the majority of babies who died of SIDS do so because during sleep, the baby suddenly stopped breathing. Okay? And I believe that the reason they stop breathing is tied to the control of respiration or the inadequate control of respiration that takes place during sleep, all right?

But there are other ways babies can stop breathing during sleep... and I've got here on this diagram two ways. Now, let's take a look at the one on the left 'cause that's the one we first mentioned. There are babies, certainly, who during sleep will suddenly develop diaphragmatic apnea and/or obstructive apnea. If that persists, there will be severe cardiovascular changes associated with bradycardia, cardiac arrhythmia, asphyxia will develop; *and* if the baby does not come out of it, or if the baby is not resuscitated, the baby will die. Now, another way to enter that route is through what I would call "feeding a laryngeal stimulation." There is enough data now to warrant the conclusion that the entrance to the upper airway has exquisitely sensitive receptors, that the slightest bit of stimulation in that area will produce diaphragmatic apnea,

and/or upper airway obstruction, and it can be persistent enough so that it will produce bradycardia, cardiac arrhythmias, and can result in death. Now, what am I talking about? What I'm saying is if a foreign substance—one drop of a foreign substance—*touches* that airway, upper airway, it can induce this reflex *in* a hyperactive individual that they can die. Now, this is not the same as saying that the baby has suffocated because they vomited a lot of stuff in the airway. I'm saying one drop could induce this. And one way of testing to find out if a baby may have this problem, strange as it may seem, is to feed the baby, because every time a baby is fed, a little bit of that milk touches the upper airway, and there are certainly babies whose breathing becomes very unusual, very erratic, very abnormal when they're being fed. It is conceivable that these babies who have these hyperactive reflexes will, when asleep, regurgitate just a drop of milk. All babies spit up a little, and if that drop hits that upper airway, it could, theoretically, induce this reflex and they could die.

Can you see this? ...Okay, let me see if I can describe it, and describe it very briefly. [*sighs*] All right. Let's take a look at the bottom trace. There's one, two, three, four, five. The bottom one: it says sucking, okay? That's nothing more than the pressure inside of a bottle, nothing fancy. When that thing goes up and down it really means the baby's sucking, okay? So you can see the way by... babies suck, and you all knew this. Anyone who fed a baby knows that the way a baby sucks is they suck: pa pa pum pum, then stop. Then go again and stop. That's what you're seeing. Now, normally when a baby sucks, they do something that we, as adults, cannot do: they breathe at the same time. Now, I would suggest for those of you hardy people who are interested in coughing that you try to breathe at the same time that you swallow. Babies, strange as it may seem, if you watch them while you're holding the little ones and feeding them, you'll notice that they keep breathing; their chest is moving. What they'll do is they'll slow down their respiration—not stop it, slow it—and then during natural pauses in respirations quickly [*clicks tongue*] swallow. They're no dummies, okay? But they're not supposed to stop.

If we take a look at this baby... let's take a look at the top channel. What the top channel says, which has “respiration, nasal,” that's just measuring air moving out of the nose. It's a tiny, tiny, little bead that measures temperature. When you breathe out, you breathe out hot air. When you breathe in, it's cooler. That just measures the temperature around the nose, all right? The next one which says “EKG,” you all know what that is. The next one which says, “respiration strain gauge,” that's a little... basically a rubber band—it's not a rubber band, it's more expensive than a rubber band—around... across the chest, and as the baby breathes it stretches. So the... [*chuckles*] strain gauge is really measuring whether the chest is moving, okay? And the last one is a cardiac tachometer. The only statement about that is that that is a

measure of instantaneous heart rate. As you see that one go down, it means the heart rate is getting slower, okay? Like you can in the middle.

Now, what happened in this baby? In this baby, who happened to be 26 days of age... and shortly after the baby started to suck, the baby stopped breathing. Stopped totally. Look at the chest... strain gauge. There's little rippling things that you see, that's just the heart beating, but you see the baby's breathing, then suddenly there's nothing, then it breathes again, nothing, breathes, nothing. This baby stops breathing—would stop breathing—whenever that baby would start sucking. And every so often, the mother would say, “You know, my baby turns blue!” Well, sure, because sometimes that baby's so hungry... so hungry. The baby just wants to eat! It's too dumb to... you know, to know enough to realize you gotta breathe at the same time some place, and so what the baby will do is continue not to breathe for an extended period of time and start changing colors. And if the baby then responds to the lack of oxygen, the baby may suddenly take a deep breath, pull milk into his airway, and cough. In fact, some of these babies get referred because they cough a lot while they're being fed. When you look at them, what they're really doing is they're not breathing, and then what they do when they start, the drive to breathe hits them, they start breathing rapidly but then pull the milk in. But these episodes have been severe enough that these babies have required resuscitative intervention to get started. But this is merely an example of a baby who stops breathing.

All right, now here's another baby. This baby was 40 days of age. And let's take a look at the sucking, and that's in the bottom trace, and first of all, what you notice it's not as clean of sucking; it's not as pretty. This baby's sucking was a little bit more disorganized. Okay, let's go to where that arrow is. You see where the arrow of the O-2-O... where the arrow is? Let's go down to respirations—where you see strain gauge respiration—and let's move over a bit to where the sucking's all about. What we see is that the baby was sucking, the baby was breathing, then while the baby continued to suck, the baby stopped breathing; the chest stopped. And then, the baby's chest started to move. Can you all see that? Should I jump up there? If I jump up there, I'll have a heart attack. Can you all see this? If you can't, tell me and I'll go up there. Thank you. All right, what you're now seeing is where the baby's chest is beginning to move. I don't know why I'm pointing. Ho ho, look at this! [*away from microphone, muffled*] Okay. Right up in there. Okay, follow it up, all right? [*close to microphone at normal volume*] That's where the baby's chest started to move, and continued to move as it went along. But! Take a look at where the—air is supposed to come out of the nose—where the black arrow is. No air is coming out of the nose. That baby's airway was collapsed or closed. Something was acting as a cork in that baby's airway.

Now, what happened very rapidly, as you look at the EKG, is the spacing between the EKG began to open up; that baby developed severe bradycardia, the baby was... when I say cyanotic, it really isn't blue; it's grey. Technically the baby looks shocky. The baby looks like the baby's gonna die. At that point, the nurse who was feeding the baby stimulated the baby, and the baby was fine thereafter. That baby was on the ward because the baby was having severe cyanotic episodes. The baby had been brought in by parents, and it turned out the nurses were saying, you know, there are times when the baby stops breathing, but it's easy to get the baby started. But there are other times they have a devil of a time! They'll put a bag on that baby and squeeze it and they're not getting anything in, and the reason is because of the obstruction. There's a cork in that airway!

The point behind the two slides is that here are two ways to happen to real, living, honest-to-goodness babies where they can develop cyanotic apneic episodes, not in association with sleep per se, but that can be triggered—brought on—in association with feeding, and this kind of a reflex could very well happen while a baby is “asleep,” ‘cause all that has to happen is a little bit of regurgitation to initiate the reflex. Now, let's take a look at what happens during sleep and we'll see the same thing, the only thing different is the baby doesn't suck! Okay, so we look at the top channel, that's the nose. There's the EKG, there's the respiration of the strain gauge, and there's the cardiac tachometer. That heavy line, with the B under it, don't look at. You will, now that I said it. Don't look at anything below B, please? What happened, very simply, is that this baby was going along, sleep very fine, very happy, minding its own business, all of the sudden the baby stopped breathing. The heart rate dropped, baby started to turn blue. If you look at the EKG, what you're seeing is the development of a cardiac arrhythmia. At about some point in the development of that thing, the nurse got very uptight, she began to get up from the console when she's watching all this, and she's ready to go into the room where the baby was because the baby was dying. Before she really got her tush up, the baby started to breathe, and the baby was fine. And she went, “Phew!” And she talked about it, later on, that there was no doubt in her mind that *this baby was going to die*. But obviously she was wrong.

I mention it because, first of all, it's an example of a situation in where the chest has stopped moving, all right? For a long period of time. It shows the development of severe bradycardia. It shows the development of cardiac arrhythmia. But it also shows something also very important: that baby came out of it with no help from anybody. Was it a near miss? That's a moot point. Why don't we, you know... that's silly. All right, but later on when we go to B, and in his sleep the baby did it again; only this time, the nurse got there and stimulated the baby. Would the baby have started breathing on his own if she hadn't stimulated the baby? Never know, because she did stimulate the baby because she was scared; she thought the baby would die. The point behind this is: number one, there's a lot of apnea; this baby shows diaphragmatic

apnea during sleep. Other point, this baby, on the ward, in the nursery, unbeknownst to the house staff, unbeknownst to the nurses, was having lots of these episodes and spontaneously coming out of them. Which one, if any, was going to kill the baby? Who knows. But that's an example of diaphragmatic apnea during sleep.

Here is another one [*cough*] only this one is here to describe, to demonstrate what we mean by obstructive apnea during sleep. And once again, let's just look at the A part; the B is just a replay of the A part. All right, what we see is... and let's look at the chest, respiration strain gauge. [*to audience*] With me? Okay. Baby was asleep, chest moved, then the baby suddenly stopped breathing for a short period of time, then the baby took a breath. If you go to the nasal thermostat, what you see is an arrow because no air came out of the nose and the baby's mouth was closed, which meant there was something occluding the airway. All right, then the baby stopped breathing again, and then started again, but still no air came out, and throughout all that, the baby was cyanotic; but the baby spontaneously came back, no help from anybody. That baby had recurring periods of, one, diaphragmatic apnea, and two, obstructive apnea... okay? And the baby was managed. These things do happen. Most of these episodes these babies come out of without any help from anybody. What I'm essentially saying is tonight... someplace in this community there are babies, who are apparently healthy, who will, sometime during this night, stop breathing or develop obstructive apnea from which they will spontaneously come back from, and in the morning when us parents go in, the baby will be essentially okay. The baby may, I think, act a little funny, so what we may do is call the doctor, and the doctor, of course, over the phone, is gonna say, "Ah, the baby's come down with a cold," and then of course, by tomorrow, the baby's feeling much better and there's no cold and nobody thinks about it. It may very well be that during those episodes the baby nearly died. But we don't know that, okay? But these are episodes that we know that are occurring and that are recurring.

All right, let's take a look at this slide. This slide, I find a very intriguing one. Now, the machines that we normally use as monitors come in a variety of kinds, but basically there are two kinds. There are apnea monitors, those that are used to pick up cessation of breathing, and then there are others that are cardiac, and these are ones that pick up the cessa... the slowing of the heartbeat. And there's a lot of discussion, a lot of debate, which is better than which. One can cut through all the nonsense and say, "Nobody knows which is better." To me—let me tell you my own bias—if I have a baby who stops breathing, I want a machine that tells me the baby stops breathing. If I'm concerned that a baby has problems with obstruction, airway obstruction, then an apnea monitor is of no value to me. Why? Because the baby's chest is moving, which is what an apnea monitor picks up. The baby's chest is moving in spite of the fact that the baby's having trouble. See what I'm getting at? So as far as the machine is concerned,

the baby's fine! The one early sign that the baby is having difficulty is the drop in the heart rate. The heart rate will drop, and drop very dramatically, and so for a baby who's obstructing, I prefer to use a cardiac monitor.

Now, when you're talking about apnea monitors, there are a variety of kinds. The most popular kind is an impedance system. Currently, the most popular kind is an impedance system where essentially you put two electrodes on the baby's chest, and it sends across a fancy current and it changes... and what the equipment picks up is a change in essentially the resistance across the chest. Now, part of the problem with this equipment is that there is a *designed* malfunction. When I say, "malfunction," what I'm saying is that ideally... an apnea monitor ought to alarm only if a baby stops breathing after a predetermined, pre-set period of time. [*laughter from the audience*] [*AS coughs*] [*strained speaking*] It's all right, I'll make it. That's all right... okay? it should alarm only if the baby stops breathing for a pre-set period of time. It should not alarm if the baby's breathing very shallow... okay? In other words, what it picks up is... it should alarm only when there's no breathing at all, and not... but pick up as respirations, very, very weak shallow breaths, okay. The trouble with this equipment is it can be made so exquisitely sensitive that it will pick up *all* movement within the chest. There are at least two things moving in the chest, one is the air moving in and out of the lungs, the other is the heartbeat. There's a heart in there that's going: pum pum pum. You can make this equipment so sensitive that it will pick up the heart pumping. In fact, it can be so sensitive that in order for that apnea alarm to go off, it will require not only that the baby not breathe, but that the heart stopped for 20 seconds.

To show you what I'm talking about: this is a baby who went home on an apnea and a cardiac monitor, *and* a cassette recorder. So we recorded at home what went on both to the EKG and the respiration. The important point here is this respiration trace, all right? The baby was breathing very very fine, and then all of a sudden you get that sort of rippling effect which got larger and larger. That rippling effect, by the way, is the heartbeat. Now, how, in God's name, is the machine gonna know the difference between the respiration and those pulses that I say are the heartbeat? To show you how serious it can get, here is another situation—same baby—in which the baby developed obstructive apnea, by the way—in which the amplitude, the magnitude of the pulsations coming from the heart were so great that it's very difficult to tell it from the respiration, and that's at the tail end, see that? So, what I'm getting at is if the equipment, the apnea monitor, is to function at all, it has to miss those heartbeats. So they decrease the overall sensitivity of the equipment, make it as not as sensitive as it might be. What do they pay for when you do that? You miss shallow respiration. Consequence: all of this equipment will have a significant amount of false alarms; they have to. It's built into the design; they must have false alarms and we're going to have to live with those false alarms until some

bright, creative design engineer comes up with a totally different system for handling and measuring respirations off a baby, than use the impedance. It's built into the equipment, there's nothing we can do about it.

What time do I have... can I go to? I don't know what... how much? Okay, if I got 15 minutes, then let me tell you about the whole concept of high risk... what it means, what it means to me. To talk about a concept of high risk means, essentially, that babies who die of SIDS are different than babies who don't die of SIDS. Let us assume for the moment—let me see if I can clarify—let us assume for the moment that all babies... that SIDS, for the most part, is an acute event that's sort of like getting hit by lightning, okay? And that the babies were, in fact, healthy, truly healthy, prior to their death. How would you go about the business of identifying the infant who was at greater risk to die? You couldn't find it off the baby. The baby who will die looks no different than any other baby. The only way you can go about that task is if there are circumstances that are high-risk *circumstances*; they're not high-risk infants, they're high-risk circumstances, all right? For the concept of the high-risk infant to really have meaning, you essentially have to have a baby that's *different*... all right?

Well, it turns out that for the most part, a large percentage of the babies who do die of S-I-D-S *are* different. I think there is now a sufficient amount of data to warrant the conclusion that the babies who die of S-I-D-S, as a group—and this doesn't apply to all of them—were not totally normal prior to death. Now, one can debate specific... and argue over specific findings whether they'll hold up or not, but I think when you put together all the evidence... [recording skips ahead] Doctor Naeye was interested in doing something with SIDS and he said, "Oh my God, if these babies are having apnea, then I know something about hypoxia; these kids are not getting enough oxygen. Let that be... 'cause I know something about that as a pathologist. I've studied adults who've had a variety of... who have had difficulty moving oxygen, and you find certain things," and he then went about looking. Now, the key—let me just say something about the process—the key to Doctor Naeye's work is not that he found it, the key is in the R-E part of research. What Doctor Naeye did was search; what we need is for this to be researched. It should be done again by other investigators, looking. If one can replicate these findings then we're on the right track. There is a reason, for those who are interested in words, that the R-E is part of research; it means "replicate."

All right, now what has Doctor Naeye found?—and we can go over very quickly some of these—he found that the pulmonary artery, the muscles in the arteries going to the lungs were thicker. I'm just going to repeat some of what was said this morning: he found that the weight of the right ventricle was heavier. He found more red cells in the liver... all right? And one can go down, and I'm not going to read them all, my point is he found a number of things. Now, some

of what's on that list was not found by Doctor Naeye... all right? When you look at seven and eight, those were found by investigators in England. So others, when they start looking, are finding them. So there's reason to believe... and some of this has been replicated. Not all. Some we're having difficulty replicating, but some has been.

I think the conclusion from all this is that these kinds of findings are such that they could not happen acutely at the moment of death. It took time to develop. *[raising voice]* If it took time to develop, then something was going on! And then we now have our work cut out for us. It now means that if we're smart, and clever, and imaginative, and brilliant, we oughta be able to detect those things; not these specifically, but the fact that something's going on while the baby's very much alive, very much alive. And that's hope! That's the light! It means we can do it. It's not a shot in the dark; it means these babies as a group—not all—are different.

Now, there are other things that have been picked up, okay? All of which... some of which I'm going to mention because I think they've been replicated now, and so it'll hold up when things finally come down. Babies who die of S-I-D-S probably do have very different cries. The cry of a baby. And furthermore that the cry of the baby at risk for S-I-D-S may be different in the very first week of life. Now that's intriguing. It may not tell us what's causing the death, but it may help us to identify a group of babies who are suspect, and then, with additional studies, begin to sharpen up which ones we ought to be concerned about. But I think there's now enough evidence to say that the cry is different. *[to audience member]* Yeah.

[inaudible question]

AS: Well, there's the... there's no consistency so far in terms of what people are finding. In terms of what the abnormalities are, but the abnormalities that were detectable in Syracuse... if you put it all together, because there's more to it than just the cry. Now, let me just finish and I'll tell you how the cry is expressed in a study that we did in Syracuse. It also turns out that there are other observations about the babies. Babies... it appears as if the baby who goes on to die of SIDS does not respond as well to stimulation of the face as babies who don't. Now, this is an earlier observation, and that was made by Doctor Rosenbluth and Anderson. In fact, it got a lot of play in *Newsweek* when it hit, an awful lotta play; and I must admit, when they suggest... when they proposed it, and I reviewed the paper—and I know Doctor Rosenbluth—I sort of made fun of her. I really did, okay? At a meeting, I was very, very un-nice. I think she's right. *[chuckles]* Okay? I think there are other evidence to indicate that, yep! In the very first week of life, these babies may, in fact, not respond well to stimulation on the face. Now, what do I mean? If you take a diaper... take a perfectly healthy baby, put a diaper across the baby's face, drop it, what do you think the baby's gonna do? *[pause while audience answers inaudibly]* Yeah,

get it off! Swipe it off, move his or her head... but, you know, come on, there's a lotta survival in our infants, all right? Babies who went on to die of SIDS did not do that as well. Now, I should also tell you that siblings of babies who died of S-I-D-S don't do it well either, as a group! As a group. Now you ask... there's another aspect. Now, this was not found on babies who died of SIDS but on the siblings. Siblings do not respond to... normally when a baby cries, starts to cry, the babies will go through... sometimes what they'll do is they'll self-quiet themselves; you don't always have to pick them up. They go through an awful lot of maneuvers to quiet themselves. It's called self-quieting behaviors... all right? Siblings—subsequent siblings—do not show much self-quieting behavior.

All right, now, if you put all the clues together, the most important clue is that it appears there are things going on in the first week of life. It appears, first of all, there's something chronic going on. There's also reason to believe that there are things going on discernable in the very first week of life: unusual cries, unusual behavior, apnea... and we won't go into that now, but there are babies that we have seen who've gone on to die who had, in the first and/or fourth week of life, oodles and oodles of brief apneic pauses. These were clinically healthy babies, so there's reason to believe that these are babies who can be identified prior to death. But here we have a profile—a bunch of things going on—which suggest that these babies who go on to die of SIDS have had something subtle going on for a period of time, and that they may be identifiable, as a group, within the very first week of life.

Now, you asked me about the cry... if you asked me the best guess about the cry as a group, all right, what seemed to differentiate is, number one, the intensity of the cry. Contrary to what I thought would happen, these are not babies who... siblings, and the babies who died do not have a weak cry, they have a very intense cry, and they are persistent because they don't quiet themselves. Now, that's not to say that this is characteristic, I'm just saying that this is what was found. I suspect what we're going to find—I suspect—is that the cry is merely an end organ; it's expressing the fact that something is not totally normal, and from the point of view of the characteristics of the cry, it may vary, to some extent, from baby to baby. What is important is that there may be unusual cry behaviors. And that's easy to pick up. All you do is let the baby cry and tape-record it, with high-fidelity equipment, and then analyze it. Nobody has to hurt the baby; no special studies, special analysis.

But anyhow, I think there's very good reason to believe that babies can be identified prior to death. There are clues about how we might do it. Can it be done now, systematically? No, it cannot be done now. Do we know whether, in fact, it can be done? No, we don't. Studies are going on to see if we can, in fact, predict which babies are at risk. If that turned out to be true, could we then move that directly into patient-infant care and prevention? No, because most of

the techniques now being looked at are much too expensive and could not be delivered. Not only that, but it would require the establishment within communities, healthcare systems, to deliver it. It can be moved more rapidly if those systems were in place already. What I'm getting at is, it seems to me, if we do our job well and rapidly—not hysterically, but rapidly—that we have good reason to believe that maybe, maybe, some very very important and useful information will come out of the laboratories that will help us to prevent at least some of the babies from dying; and that we ought to move now, increasingly, in the direction of being set up to handle babies that we now know to be at increased risk to die of SIDS!

Who? The babies who have recurrent apneic cyanotic episodes, we know that. We know infants born into families where there's been a previous SIDS death. I think, for example, in this community we ought to have, you ought to have, physicians who are interested, concerned, and have to capability of following, studying, watching, and trying to help keep at least these two groups of babies to prevent them from subsequently dying. Even though the risk may be low, still—you know, in terms of absolute numbers—still, they can start working and work now. What they will need is your support. They will need a commitment, and they will need a commitment on the part of the community. They'll need a commitment on the part of the state. This is not a job they can do alone in an isolation. They really have to have... and I'm serious, having gone into a new community like Baltimore. What's made the difference in Baltimore, clearly, is that the community has made an expression of concern. They would like to do whatever they can to keep their babies alive. There are clues. They would like these clues to be explored and utilized at the earliest possible time, and there is a lot of community support in Baltimore for what? For the SIDS effort that's going on. I'm saying, if you expect something similar, you're gonna have to support it... okay?

One of the things I'd just like to leave you all with—there's lots more we could talk about—but let's start off with a question. There's one thing, and that's that statement of hope. I have every reason to believe and hope that I will become a grandfather—not that she's pregnant yet—but I feel very confident, personally, that when all the excitement and all the leads that are now coming out, with that light that appears to be at the end of that tunnel now getting brighter and brighter, that if we collectively do our jobs well, that we will find that SIDS, as a group, will be predictable and preventable, and Dr. Steinschneider will become a grandfather. Thank you.

[applause] [about one minute of silence at end of tape] [program ends]