

Seizing Life, episode 127
Searching for Answers, Providing Support, and Understanding Grief After the Death of a Child
Guest: Dr. Richard Goldstein
(Transcript)

Kelly Cervantes: Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy. We have spent several episodes of the podcast discussing SUDEP or sudden unexpected death in epilepsy, which occurs when a seemingly healthy person with epilepsy dies for no obvious reason. In observance of SUDEP Action Day, which this year is on October 18th, we are speaking with Dr. Richard Goldstein on today's podcast. Dr. Goldstein is here to discuss research being conducted within the category of sudden unexpected death in pediatrics, or SUDP, which includes SUDEP and several other subcategories of early childhood mortality. As a notice to those who may have experienced the loss of a child, we will also be discussing how this research intersects with Dr. Goldstein's work with bereaved parents. This is a difficult conversation to have, but I think, if you choose to listen, you will understand the importance of addressing these issues.

Dr. Goldstein, thank you so much for joining us today. I have been looking forward to this conversation, as difficult as it may be. And full disclosure, I have my box of Kleenex here, if I need them. But your work intersects rather remarkably with my life, and I'm really excited to talk to you about the work that you do. Now, you research sudden unexpected death in pediatrics, which SUDEP, sudden unexpected death in epilepsy, falls into that category. And I'm wondering if you can sort of explain to us what it is that you study, how SUDEP fits into that, and yeah, that's the question.

Dr. Richard Goldstein: Okay, Kelly, I'm really happy to be here and talking to you today. We kind of made up this SUDP. There's a word soup of diagnoses that we deal with. 10% of the children who die in the United States die without a cause that can be explained. And this program was initially founded to pay attention to sudden infant death syndrome, SIDS. And SIDS, because there's skepticism about whether it's really a diagnosis, we had to expand our view and also include deaths that were noted on the death certificate to be unexplained, just undetermined causes of death. And then, because risk factors for SIDS, including the prone position, which, in some ways, is a risk factor for SUDEP, people became more aware of it, we then had to include accidental suffocation. And altogether that is SUDI, sudden unexpected death in infancy. That infancy focus then excluded anyone over one, who died under unexplained circumstances.

And so, our work has expanded from SIDS and SUDI, now to also include SUDC, and that is kind of what we mostly think about as SUDP, sudden unexpected deaths in pediatrics. SUDEP is important, because number one, because it's been extraordinarily influential in the work that we've done and understanding why these children die. It's also important, because there's a clustering of death in very early life, and then, there's a raise later. And when it raises up later, these are children and young adults who've been alive longer and often have expressed the diseases that are, ultimately, a vulnerability we think for the death. And so, that's our project here is this huge reservoir of not just diseases

that are not understood, but mechanisms of death that are not understood. And that's what we kind of consider SUDP to be. We think that pediatricians should be thinking about all these things together.

Kelly Cervantes: You are the Director of Robert's Program on Sudden Unexpected Death in Pediatrics, and that is at Boston Children's Hospital. Can you tell us about that program? You touched on what it is that you're researching, but what is your process? And how do you connect with these families?

Dr. Richard Goldstein: So Robert's Program looked to something called the Undiagnosed Disease Network, that's a network from the NIH for living patients. It's a major benchmark for us. So this is people that, on average, on average, go maybe seven years going from doctor to doctor. It's called the Diagnostic Odyssey, knowing that there's something wrong, no one can fully diagnose it, and they go to the NIH. And the NIH throws the kitchen sink at them. And that includes medical history review, that includes diagnostic testing, and it importantly includes genetics. Robert's Program is similar to that. It's an interdisciplinary group. It involves geneticists, epileptologists, cardiac doctors, metabolism experts, pathologists, neuropathologists. It has a research arm. And cases come in, either because parents prompted it or because their doctor prompted it. And we do an evaluation much like the Undiagnosed Disease Network does, chart biopsy, genetics, second review of the autopsy results, and then we report back to the parents.

We begin with a conversation with the parents. That is kind of standard medical history, but it's also we're trying to understand the child in that context. And it's important to us to answer those I call them two o'clock in the morning looking at the ceiling questions. There are a lot of questions that parents have about whether they should have called the doctor with this small thing, whether this was important, but they're kind of embarrassed to ask whether it was important. So we see our mission really as trying to answer all those questions. It's hard enough to go through life after this loss as it is. And so, we try to unburden the families as it is. And so then, after our evaluation, we sit down with them, we say what we have, and if there are things to evaluate, we explain what those things are. If there's a cause of death, we explain it, or a susceptibility, we explain it.

And we also tell them the things that they're off the hook for. I think parents really feel on the hook for a lot, and that includes just risk to the other children. We have three questions that we sort of deal with, "Why did this happen? Should I have known? Is there anything I could have done to prevent that?" That's a very horrible question for parents to have. And then, third, "What does this mean to our family moving forward?" And some of that's family planning and some of that is living in the aftermath of loss as a parent or as a member of a larger family and what that looks like in this new world of normal that they find themselves in and what they might help themselves by not fighting themselves over and also paying attention to.

Kelly Cervantes: You touched on so many important pieces, why families need to know and why this work is so important. I do know that some of the projects early on in the program were funded by a CURE Epilepsy grant. And I'd love to sort of hear from you how these sudden unexpected deaths, where have you found that crossover with epilepsy?

Dr. Richard Goldstein: Yeah. I founded this Robert's Program with a really extraordinary neuropathologist. And her work was focused on serotonin, and serotonin is important for epilepsy. But as we put together this new platform, we very quickly discovered a few things. The first is that, in Dr. Kenny's work, she had already shown that there was a relationship between SUDC, sudden unexplained death in childhood, and febrile seizures. And that was in the child, but also, within the family's history. And so, we took that kind of as a clue to look more carefully at epilepsy overlay. And then, our first really momentous work in Robert's Program was an observation in the temporal lobe. And what we found there, what Dr. Kenny really found there, was that about 40% of children who die from SIDS and 48% of children who died from SUDC have changes in their temporal lobe that had only been described in temporal lobe epilepsy.

So now, we had febrile seizures, we had markers for epilepsy in their brains, and then, we took our first 10 cases, our first 10 SIDS cases, that had these findings in their brain, and in two of them, we found a deleterious mutation variant in the SCN1A gene. That's a Dravet syndrome gene. It's associated with a febrile form of epilepsy. And we were so excited, but we needed some work on a broader population. And one thing that's unique to our work here is that, in many areas of medical research, you have a clinical service that's associated with it, and you can get a little bit of offset for billing.

You can do a little bit of research on the side and billing. And as parents whose children have died learn quickly, you lose your insurance when you've died. And so, there was really no money for this, and we needed a kickstart. And CURE was so receptive, and it was the springboard to our program. It led to an NIHR 21, and it was the testing ground for everything that we've been doing ever since. That was 2013. So I don't think we'd be here if we hadn't had that very timely CURE Grant.

Kelly Cervantes: That's incredible to hear. And I'm so happy that CURE could be a part of this incredible research.

Brandon: Hello, this is Brandon from CURE Epilepsy. Sudden unexpected death in epilepsy, or SUDEP, occurs when a person with epilepsy dies for no known reason. It's estimated that SUDEP takes the lives of over 3000 people living with epilepsy each year. CURE Epilepsy is committed to unraveling the mysteries of SUDEP. Our work has helped establish respiratory rest as a leading cause of SUDEP, among many other important findings. Learn more at CUREepilepsy.org. Now, back to seizing life.

Kelly Cervantes: Some of the results of what you were seeing is that there is this incredible connection between these unexplained deaths and epilepsy and seizures. And I have to wonder how much of SIDS, how much of these unexplained deaths is actually SUDEP is actually epilepsy. And do we have any idea, if that's the case, why do these children die after their first seizure?

Dr. Richard Goldstein: Yeah, so some of it's nomenclature, right? So you have to have more than one seizure to have epilepsy. The other part though, just to be really fair about the state of the science, I think we've gone from thinking there is a SIDS, there is a reason for SUDEP, there is a reason for SEDC, to now understanding that it's a heterogeneous phenomenon with commonalities that work across it. It's not all seizure related and epilepsy related, but that's an important subset.

The other thing is, what are we looking for? So the state of science now is looking at genes as explanations for known disease. There's also the possibility that this is entirely unknown disease or involves... We tend to think about single systems. Like there's a group at Baylor, that does really fascinating group work on a long QT syndrome, a cardiac arrhythmia gene, and showed that this gene KCNQ1, that, in those deaths, this is animal work, but in those deaths, there's a dialogue, because that gene is in the brain as well and that actually the cause of death might more properly be related to the epilepsy and postictal phenomenon than it is to the arrhythmia itself.

But so long as we only looked at that as a cardiac arrhythmia gene, we didn't even understand this new category of disease. So that's going on. And then, the other really critical feature for us working with infants, infants don't survive, these babies that died largely before six months, they don't typically survive long enough to express the disease. And it is likely, I would say, that there's a whole category of disease that no one's really looked for, that it's presenting as sudden death. And until we start to do the sequencing and then, clip those genes out and find animal models to test it and become a little bit more sophisticated in thinking about family history and whether the mother's mother's brother's disease has anything to do with the child has died.

And that's a whole new complexity of disease brought in by the Undiagnosed Disease Network, but also, really by epilepsy research, I think, in many important ways. I think, bottom line, it's complex, heterogeneous disease. It's probably not simple Mendelian, "You got this gene, you have this condition," and it's kind of exciting. And it's tricky medicine, because you're constantly budding into either the limitations of science or uncertainty.

Kelly Cervantes: You are essentially saying what we have been told with my daughter who passed away four years ago now, we never had a diagnosis. And then, a couple months ago, we sort of got that call that, three and a half years later, "Maybe this gene is the one. And do with that what you will." It's amazing to see how far we've come, particularly with genetics and postmortem study like this. It is absolutely wild to see how much further we have to go. And so, incredibly

grateful to you and your team for doing that research. But that's not all you're doing. You are also a palliative care physician.

So on the clinician side of this, you're working with bereaved families and grief, and you are in a unique position, I think, as a researcher. I've talked to so many researchers, and they are not necessarily working directly with the patients. It is a number. A lot of times, these patients aren't even names, because it's all anonymous. And you are in this position, where you are crossing very much into the personal. And I wonder how that has affected your research and how you balance being a part of both sides of this experience.

Dr. Richard Goldstein: Yeah, I think palliative care is a field where we understand that biomedicine occurs in a lived reality. And these are dramatic, profound moments in people's lives, and people need help for that. And there is expertise that is really useful for that. And I guess I allow that to inform a lot of what I do. They're separate audiences really. They really are. They're separate audiences, except for the parents. And in palliative care, I'm in some really what we say are hard rooms. I'm having some very difficult conversations about things that I don't even feel equipped to talk about sometimes. And parents that are just struggling with this and are so overwhelmed with what is occurring shouldn't be expected to be able to deal with at a single blow.

And I brought that into this work, because honestly, talking to a parent who has just lost their child, that's the hardest room. That's the hardest room. And if you add for the fact that it just doesn't make sense and they're expected to leave their baby to, I don't know, the city morgue, with no explanation and no reason and, in some cases, to be investigated for their role in that, I don't know, I don't think society really has that right right now. I really don't. And so, I, and everyone in my group, and that's including the most refined scientist, they're stirred and devoted to this cause, just because we're so aware of what happens.

Kelly Cervantes: But you've gone a step further and you have developed programs to help these bereaved parents. And I think that's so incredible and so remarkable. Talk to us about these programs that you've created.

Dr. Richard Goldstein: Yeah, thank you for recognizing it. We offer a parent support group. The program of the group is based on the psychological concept of graded exposure. So what we do is we bring the group together, and we have different themes that we explore. And those themes get deeper and deeper and deeper as time goes on. And this is not individual psychotherapy. This is, and maybe some in the audience will understand this, and maybe you will, this is, what do you say when someone says, "How many children do you have?" What do you say when you are at the supermarket and the cashier says, "Hey, whatever happened to that cute child of yours?" This has to do with "It's Christmas and the whole family's coming together and I can't bear to walk into that room, yet I want my child's memory and my child to be part of that. Where do I even start?"

It has to do with, who deserves to know? You can't bleed on demand to everyone. That's something that parents who've lost child have to deal with. And how about just being able to look at your child's picture and tell their story in a way that shares the joy that your child brought and the delight of your child in this world? Those are practical issues that parents deal with in the absence of their child and with the pain of loss and the yearning that so swoops in. And so, that's what those groups are intended to do, and we feel good about them. We also recognize that there are benefits to individualized therapy, but that there's a special kind of support that comes from other parents that have been through the same thing. And that's called peer support. And peer support is something that's not very well studied, but we're putting together a training. It's going to be rolled out next month. It's an international training for peer support counselors, so that'll be rolled out. And then, we also have this program of research in grief and what grief looks like most of the time.

Kelly Cervantes: I feel everything that you're saying. The peer support in grief is so, so important. And that was a breakthrough for me was the first grief retreat I went to. And I got to meet these other parents who had lost children. And I hear from so many others too, they're like, "You lose a child, and you don't feel like you fit into your normal social circles anymore. Because how can anyone understand this loss?" And then, you go into a room full of people who do get it, and then, even if they didn't lose a child the same way or their child was a different age, it's still this similar experience.

And you get to, for the first time since your child died, feel a little bit normal again in this group of people. And I wrote a whole book about it called Normal Broken. That's what this is... And I think it's so incredible that you are facilitating this, because I don't think I would be where I am in my healing journey without both the research aspect of getting a better understanding of what was happening with my daughter, but also having that peer support and having a group of families where I could feel normal and can commiserate over answering the question, how many children do you have?

Dr. Richard Goldstein: You don't have to double explain everything. Your defenses can come down. You can trust. You don't have to read what's going on behind eyes in the same way. I think it's also powerful that, all over the world, really, it's probably through all time, this is what people do. You have this terrible thing, and you look, not necessarily for guides, but for people who can offer a different kind of empathy, not just the sort of looking down, nodding your head saying, "Oh, that must be so sad." But to understand what those days are like, when you physically are aching from your loss. And to understand all those awkward moments of well-intended people who don't help or people that let you down. Or whatever it is, that's all part of it.

Kelly Cervantes: What you're talking, everyone experiences their grief differently and they go on their own grief journeys. But I love that you're highlighting these commonalities, because grief can feel so isolating. And you read about Kubler Ross' grief stages, and I thought, "I get to acceptance and the golden light shines down, and I've

won grief or something," and it doesn't work that way. But there are these commonalities. There are these pieces that we share as people who have experienced deep loss. And we sort of touched on a few of the idea of normal in grieving, and I know that, in grief, we can feel incredibly abnormal. But what are some more of these commonalities that you see? What are you finding in your research of this kind of loss and grief?

Dr. Richard Goldstein: Well, thanks for that question. Before I answer, I feel like I need to say, I'm not telling anyone how they should feel. I think it's very easy to look at this, you made a comment about Kubler Ross, to feel like you're measuring up against some normal, so please don't take it this way. We've been interested in attachment really. But to us, the major question is how parents maintain a connection with their child in their physical absence. Grief is complicated. It's traumatic. There are things that happen that are shocking, that are very arresting to see or to be treated that way or to be so overwhelmed. And that is very often not between you and your child, but between you and the circumstances or the EMTs that come in or the emergency room doctors. That's important, but that's not what we deal with. People are often very sad and depressed.

And again, that's a really important problem. But that's between you and yourself, right? The depression is you looking inward and coming up very low and having certain set of feelings that go with that. We're interested in between you and your child. And we study this somewhat controversial diagnosis called prolonged grief disorder, and I want to explain why it's so important to us. Prolonged grief disorder isolates the attachment features of loss, and it describes the emotional pain and yearning. But then, it also allows us, if we use that in our research, it also allows us to understand other components of loss, like role confusion. "Who am I as a parent? If this could happen to my child, how can I ever trust myself again?" It allows us to isolate anger.

"You mean this is what happens? The world is just so interested in moving on? You mean this is the system? This is the way the system is set up to treat me and to treat my baby?" It deals with avoidance. "My nephew, who's the same age, I feel terrible, but I feel so bad being around him now. It's just too overwhelming and too distressing." And so, those are just three examples of components of prolonged grief disorder that we think are important, because it allows us to understand the lived experience of navigating a world without your child, but holding onto the attachment. So prolonged grief disorder, in my mind at least, is an attachment disorder. And it's important to us that way. It's important to us, because we don't have resources to take care of people. So who's most at loss? Who's most at risk for more strong reactions?

And we know that the people that are most at risk are a little older. They have a history of depression. We also know that your prior psychological history predicts ups and downs, that has different shapes for people who are anxious, for people who have other children, for people who have addiction and substance use issues. And we think that that's important, because it allows us to

direct resources. And lately, we've been focusing in on life with loss. In earlier research in palliative care, I did home interviews, and I found that many parents have a box, a drawer, and they put things aside from their child.

And I was interested in the behavior around that, and we did it on almost 400 SIDS mothers from all over the world. And everybody has it, and everybody goes to it a lot, a lot of times a day. And they cry and they smell and they cuddle it. And that complex way of being with these objects is to me so beautiful. It's private. It's restorative. And so, we did some research on that, and then, we opened it up a little bit more, and we looked at what parents do over time to keep their child present in the world.

What are the ongoing imperative responsibilities that you face having a child who's not here, who's still a member of the family, who's part of your heart and your feelings, on their birthday or on, I don't know, Christmas? And so, we've looked at that process, and the work we have, that we'd like to get started, looks at how loss affects parenting. Because we tend to think about loss as an affliction, as damage. And what I've found actually is that there's a kind of gratitude and in a day-to-day attention in parents after loss, that is almost always present and is something that's worth looking at, because I think it's helpful for parents to know, when they're so overwhelmed in the beginning and asking how they can go on, just some more information about how people do go on and that the world will be beautiful again.

Kelly Cervantes: Yeah, I think that is so incredible. Excuse me.

Dr. Richard Goldstein: Kelly, this is it. This is it. This is exactly what it is. And I think people are embarrassed about it or they feel like they need to leave the room when it's there. No, it's an open declaration that your baby still matters, your baby's still here all the time. On a daily basis, they float into your life, and I think we need a different kind of dialogue around that. I think it would be helpful for the parents who feel burdened to also recognize that it's a certain beautiful feature of your life, hard as it is.

Kelly Cervantes: As you're saying that, talking about the box, and I have two boxes, but Adelaide is everywhere in our house. This wallpaper right here that I have framed was in her bedroom. That dialogue and that acceptance of grief, and it is so important. And I so appreciate the grace that you have just provided me, as I have my moment, but also the light that you provide about how it does get better. Because it does, even though I'm four years out and still a sobbing mess sitting here, this is not my every day.

Dr. Richard Goldstein: Well, I'm like the trigger waiting to happen.

Kelly Cervantes: This is certainly not my every day, but I do have an additional gratefulness for this life that I have. And it's bizarre to say, but I often even feel lucky, which is I know so backwards. Because how can I be lucky I lost a child, right? But

everything else that I do have in this life, it allows me to feel so grateful for the things that I do still have and appreciate those things. And the perspective that I have in life today is just so wildly different from what I experienced 10 years ago. The work that you are doing helping these families, in addition to the research for giving them answers, it is incredible, and it is invaluable. And we are incredibly grateful to you and your team. Based on your experiences on both sides of the research and as a clinician, I wonder, is there any words, additional words of hope or advice or comfort, that you would want to share with parents who are grieving the loss of a child, from your experiences, that might help?

Dr. Richard Goldstein: I don't know. I feel like the parents teach me more than I have to teach them. I do feel like, just trust the love, not just, trust the love, trust the love. It's going to lead you. It's going to lead you to places, and it might not be a parent. But if you trust it, it's a good thing in this world, and it's about you and your child. And it ought to be here, and there's no apologizing for it.

Kelly Cervantes: I love that. Don't apologize for your love. Don't apologize for your grief. Dr. Goldstein, thank you. This has been an incredible conversation, and I'm just so appreciative. Thank you.

Dr. Richard Goldstein: Thank you for having me.

Kelly Cervantes: Thank you, Dr. Goldstein, for sharing your research and insights about early childhood mortality and the grief process of parents who have lost a child. We know that this is a difficult and painful subject for many parents in the epilepsy community, but it is also an important and necessary conversation to have. CURE Epilepsy aims to raise awareness of childhood mortality and epilepsy and increase understanding of SUDEP, so that we can help mitigate risk and support research that may ultimately prevent SUDEP from ever occurring. If you would like to help us in our mission to find a cure for epilepsy, please visit CUREEpilepsy.org/donate. CURE Epilepsy, inspiring Hope and Delivering Impact. Thank you.

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