Hallway Conversations – SUDEP and PAME Conference Wrap-up

In this episode of Hallway Conversations, Joseph Sirven, MD, Professor of Neurology at Mayo Clinic Arizona and Editor-in-Chief of Epilepsy.com interviews Drs. Orrin Devinsky and Daniel Friedman, from the NYU Comprehensive Epilepsy Center about SUDEP and the PAME Conference Wrap-up.

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Dr. Sirven: Hello to everyone out there and welcome to Hallway Conversations on Epilepsy.com. My name is Dr. Joseph Sirven, Editor and Chief of Epilepsy.com. Today is Wednesday, July 18, 2012, and we're here to talk about a very important topic that we've covered in some degree in the past, but we want to talk about a kind of a different issue surrounding it and that pertains to the issue of death or mortality in epilepsy.

On June 21st to the 24th in the Chicago suburban area, there was a major conference, otherwise known as a PAME Conference, Partners Against Mortality in Epilepsy. This was a joint effort, SUDEP coalition partners from the American Epilepsy Society, the US Centers for Disease Control and Prevention, CURE, Epilepsy Foundation, Epilepsy Therapy Project, the NIH, and SUDEP Aware. And this was a rather amazing aggregate of both the patient, the advocacy, government, neurology, the physician specialty all coming together to deal with a certain issue.

So we wanted to kind of devote a little bit of time to talk about what was learned. What were some of those messages? To join us today are no strangers to Hallway Conversations, and both of them are coming from New York, and that is Dr. Orrin Devinsky, Director of the NYU Epilepsy Center and Dr. Daniel Friedman who is an Assistant Professor of NYU and also at the Epilepsy Center in New York, so to Dan, to Orrin, welcome both to Hallway Conversations.
Orrin Devinsky: Thank you very much, Joe. It's a pleasure to be here.

Daniel Friedman: Thank you. It's good to be here as well.

Dr. Sirven: Great. Well, let's start off so our readers who may not know, even though they are probably few and far between, Orrin, can you just tell us about your current role and how this relates to SUDEP and epilepsy, and then I'll ask Dan the same question.

Orrin Devinsky: Yes, so I've been an epilepsy physician and epileptologist for a little over two decades now, and as all doctors who see people with epilepsy, especially the epileptologist because that's the vast majority of our patient population, unfortunately, since early in my practice in fellowship, I have had people who are close to me as patients who have experienced a sudden unexplained death. And in the first few years, you know it seemed like something that this happens and there were papers and literature on it, and it was essentially a mystery, and no one really understood it.

Over the past five years, I think largely motivated by our colleagues in Europe who have taken a very keen interest in this and have done some great studies as well as some good epidemiologic studies in the United States earlier on, it's been clear to me that it's an area where there probably is an immediate short-term opportunity to learn more and to try to reduce the frequency of SUDEP, and that's how I got interested.

Dr. Sirven: Very good. Dan, same question.

Dan Friedman: I haven't been in this business for as long, but I'm an epileptologist who sees teenagers and adults with epilepsy, and particularly hard-to-treat epilepsy where the risks of SUDEP is a fact of life for many of my patients, and I'm very interested in identifying ways we can mitigate that risk by looking at the potential clinical risk factors and pathophysiology of SUDEP and identify things we can target for intervention.

Dr. Sirven: Very good, which we are going to get into in a moment. Orrin, kind of talk us, tell us about the PAME Conference and I guess to start us off, your biggest kind of take-home message that arose from this very comprehensive meeting.

Orrin Devinsky: My biggest experience at the PAME meeting was that it was an extraordinarily valuable meeting in that they were able to assemble a great number of experts from around the world on SUDEP and that simultaneously, there were a lot of individuals from disease organizations like ETP and CURE, and the Epilepsy Foundation was very well represented and other SUDEP Aware, FACES, and then many just families who have been unfortunately directly affected by SUDEP. So I think it was a very unique meeting for three days to have these different groups all together, all interacting.
I think for some people doing research on SUDEP, seeing the families and hearing their stories, and seeing the kids’ pictures gave it a remarkably poignant and special relevance. So that was kind of my feeling on the meeting, and as far as the overall take-home message is that there is an extraordinarily large amount of research and interest in SUDEP now from the number of publications coming out on the topic of SUDEP to the number of basic scientists and clinical scientists interested in this area.

So I think that was the biggest single take-home, that the interest in this area has gone up dramatically, and there is activity going on everywhere from researching brain stem serotonin neurons to epidemiological studies to medical examiner studies to pathophysiology studies, that they’re all going on in parallel and that one of the challenges will be to maintain communication, and that's what this meeting was about between all the different groups.

Dr. Sirven: So a lot of hope when you look at all of these folks that are kind of coming together.

Orrin Devinsky: Very much.

Dr. Sirven: Dan, same question. What was your take-home message from the conference?

Dan Friedman: I think I'd like to echo a lot of the points that Orrin made, but the one thing that struck me is the power of patient advocacy organizations as research priorities. I think that in this area as opposed to many other areas of epilepsy, the driving force, the motivation for bringing us to the forefront of a research agenda has been the family members of people who have lost their lives to epilepsy.

I think the other important point that was mentioned several times in the conference and I think something that we need to hit our funding and legislative bodies with is that epilepsy is a disease that has a very high number of lost-life years, of patient-life years, so that the concept, the way of thinking of that, that while epilepsy is less prevalent than Alzheimer disease or some other common neurologic disorders, the number of life years lost as people with epilepsy, mortality from seizure-related causes is tremendous and how it strips those. And we should use that to get more resources allocated for the care of people with epilepsy and research into prevention of mortality in epilepsy.

Dr. Sirven: You know absolutely. I mean when you think about it, those things should kind of drive us to the issue of prevention, and Orrin, I know you moderated a session on SUDEP prevention. Can you kind of, that’s always such a big topic because that’s what most people ask, what do we do to make sure this doesn’t happen? Can you sum up maybe some important points that kind of arose from this meeting on that topic?
Orrin Devinsky: Yes, I think it was a very fruitful discussion by some great investigators and to begin with, we talked about what are some of the modifiable risk factors? And the big one that shouts itself out is seizure control. A very big risk factor for SUDEP is ongoing seizures, especially tonic-clonic seizures, and so everything that patients who are taking their medications reliably, trying to avoid sleep deprivation, avoid excess alcohol intake, and other factors, and coming up with plans ahead of time.

Like if there’s a GI illness that causes diarrhea or vomiting and they can’t take down their medications, to have a plan whether it’s dissolvable clonazepam wafer or something like that, so that they can be protected for short periods and try to avoid seizures, especially big ones. It’s easy to say and hard to do for many people, but I think that ties into the question of education. And I think one of the things we need to do is educate patients about the risk of SUDEP and let them understand that one of the consequences of not taking medicines or not sleeping and having a breakthrough seizure is the potential for not only a big tonic-clonic seizure but the potential for SUDEP, and we’re not good at predicting when and where it’s going to happen.

We think that the people with more frequent seizures are at higher risk than they probably are, but unfortunately SUDEP can happen to people who have had only one or two seizures previously in their life. The other big message I think for which we don't have a tremendous amount of data, but there are several studies that strongly suggest that people who sleep alone without someone in the room or someone monitoring them by sound or other way, that they’re at higher risk for SUDEP than people who sleep with a partner or someone observing them in the room.

And so there are now several different alarms, a couple of wristwatch alarms, a couple of motion detector alarms that go under the mattress, and several other newer devices being developed that can signal other people in the home that a seizure is occurring and allow that other family member or caretaker to potentially go in the room and may simply be rolling the person over on their side, and in the right setting, that may be potentially life-saving. We don't have data on that, but it's certainly something that makes sense and fits with the data, and at high-risk people would certainly be a reasonable precaution to consider.

And then the final area is just educating more patients and more doctors about SUDEP and about things that can be done such as minimizing seizure activity, and the potential for alarms to try to reduce the frequency.

Dr. Sirven: So in essence, it really centers on the education and perhaps even use of technology or people, depending, to kind of serve as that extra monitoring piece.

Orrin Devinsky: Correct, yes.
Dan, speaking of technology and things in that direction, I know you gave a presentation on devices in SUDEP prevention, which can kind of cover a lot of different things. Can you kind of further some of the points that Orrin mentioned or perhaps provide some other ones with regards to what you kind of learned with regards to the devices and SUDEP prevention as a whole?

It's certainly an exciting development in epilepsy care there. People have responded to the idea that alerting somebody about the occurrence of a seizure may be helpful in preventing injury or deaths. This started out with devices that are currently available that detect rhythmic motion, the kind that are typically associated with tonic-clonic seizures, which we think are the most dangerous kind of seizure with respect to SUDEP. These very simple and cheap devices are pretty effective, although they are plagued with false-positive readings.

What's exciting is the next generation of devices that are being developed that use multiple, different kinds of simple sensors, so not just movement sensors but also heart rate sensors or other physiological measures to improve the specificity of seizure detection. What's hopefully in the future is coupling that detection with a feedback loop that we want to be able to offer something that for patients who don't have a caregiver in the next room or a caregiver that's available to come and check on them, something that we'll learn from studying a physiology of SUDEP perhaps, and something that maybe animal models will help us understand.

It's important to stress that no device has been proven to prevent SUDEP, and certainly they're not FDA approved for even seizure detection, the ones that are currently available. And so we have to serve caution with the promise of the devices in the fact that they make sense to us with the possibility that we're providing false comfort to some of our patients, and so it's just something to consider.

So a lot, the sky's the limit if you will but nothing that as yet gotten an approval for this.

Correct.

Okay. Orrin, I know that it was mentioned a little earlier that we count numbers of the number of cases of sudden death that occur in epilepsy, and they really are somewhat high, but we still have problems in knowing our true numbers of people who actually die from epilepsy, from seizures. Orrin, I know you also spoke in the conference about registries, case collections, how people tally the census, if you will, of this terrible thing. Can you kind of tell us what's the latest in terms of what's happening in terms of measuring these cases that occur?

So I think one of the big challenges ahead is to do more surveillance in the United States on SUDEP occurrence, which has not been a strongpoint of our country. We don't have the medical
Dan Friedman, myself, and many others around the country representing a broad group of epilepsy specialists, cardiologists, epidemiologists, medical examiners, representatives from the major lay organizations have formed the North American SUDEP Registry. And our hope is by doing this that we can start systematically collecting more information on SUDEPs hopefully sooner around the time that they occur so the information is more prospective and that in many cases we can get tissue, either brains or DNA, down the road maybe other organ tissues like the heart or lungs that may be involved in SUDEP.

And by doing this, I think that without a really strong tissue and DNA repository, our scientific understanding of SUDEP will be severely limited. And hopefully by advancing this tissue, DNA repository, we will be able to really both our understanding and our ability to target therapies.

Dr. Sirven: Yes, I mean I imagine that that is going to be the only way we kind of make the next big move on that, so I appreciate that. Dan, you know as you look at the conference as a whole, what's the next evolution? What should arise or what is our actionable things to do that are likely to emerge from this conference, or what's the future for this conference?

Dan Friedman: I think the future is, what struck me at the conference is that there was excellent discussion and good summary, but a lot of things, there was not that much in terms of novel data. A lot of the information that was discussed has been around for a while, or perhaps we've had some additional experimental data that has emerged. But I think there's a huge initiative underway that will provide us with better understanding of the epidemiology of SUDEP from the CDC and NINDS initiative that Orrin just mentioned. I think there's going to be a better understanding of SUDEP physiology and genetics that will emerge from the NINDS funded Centers Without Walls that are in the planning phases.

So I think that hopefully for the next PAME Conference, we'll have a lot of new and exciting concepts to talk about based on those results. I think the other thing that I would hope for in the future is that there's, while SUDEP was the focus of this conference, there will be other, there will be discussions, more in-depth discussions of other causes of mortality in epilepsy, specifically suicide because our understanding of this very significant cause of death in people with epilepsy is rather limited, and I'd like to see more research and discussion to that down the road.

Dr. Sirven: Fair enough, and a good point that there are other causes of death in epilepsy other than the
sudden death which need to be looked at. We're in our last minute to minute and a half or so. Orrin, I'll start with you. Anything else or take-home message for the people who are listening or downloading this today that you want to share just so that you have a chance to leave that take-home message with our viewers, listeners, and readers of the site?

Orrin Devinsky: I think, you know my biggest thing is I think most people, I imagine, who will hear this don't have a family member with SUDEP and are probably either have epilepsy or have a family member with epilepsy, and I think it's important to make sure people understand SUDEP is uncommon, that for people with well-controlled epilepsy who live in the community, the rates of SUDEP are probably less than one per thousand per year. So in someone's lifespan, it is extraordinarily unlikely to occur if you live with epilepsy for 70 years.

Having said that, for those people who have very difficult-to-control epilepsy who are seen at epilepsy centers and who are thinking about surgery or thinking about vagus nerve stimulation, or have tried eight drugs before and still have seizures, unfortunately SUDEP is more of a risk and I think for those people, thinking about some of the monitoring devices Dr. Friedman mentioned, thinking about being exceedingly good with taking medications, with getting good rest, with avoiding alcohol possibly completely or no more than a drink or two a day for adults, would be really important messages.

But it's got to be understanding SUDEP; part of it is understanding risk and obviously, every person faces risk of unexpected things. Most of us drive cars, and that's probably the biggest risk in our lives when we put it to the side. I think this is one of those risks that's worth understanding and thinking about because I think there are things to do to reduce it.

Dr. Sirven: Dan, last words that you have as a take-home message?

Dan Friedman: I think that the meetings like this and the excitement around it hopefully will trickle down into the greater epilepsy and neurology community, and we'll educate our colleagues, our patients, and hopefully the medical examiners so we'll be able to obtain better information about SUDEP, better counseling of our patients about SUDEP risks, and even just awareness I would hope may impact SUDEP rates.

Dr. Sirven: Wonderful advice. To Orrin and Dan, thank you so very much for speaking with us today. I know you all have been on these podcasts in the past. I know we'll call on you both again, but thank you both for today. I know for those who may be wondering, I think there's a thunderstorm out in New York. There's not one here in Phoenix, so that may have been that little kind of, some of that noise you were hearing. But thank you both for your participation today.
Orrin Devinsky: Thanks, Joe. Take care.

Dan Friedman: All right. Thanks, Joe.

Dr. Sirven: And to everyone out there, thank you so much for joining us. I hope you have learned something from this Hallway Conversations, and for the future, please join us again for another podcast of Hallway Conversations on Epilepsy.com. Until that time, have a great day. Thank you.