Seizing Life – Episode 33 Mike Adamle Tackles Life with PTE and CTE Guests: Kim and Mike Adamle

Kelly: <u>00:00</u>

Hi, I'm Kelly Cervantes and this is Seizing Life, a weekly podcast produced by Citizens United for Research in Epilepsy Cure. Today I'm excited to welcome Kim and Mike Adamle to the podcast. Football fans may remember Mike from his playing days at Northwestern University and his six years in the NFL, from 1971 through 1976. You may also recognize Mike from his long and successful career as a broadcaster and sports anchor. He worked for NBC sports, ESPN and American Gladiators, among many others in his nearly 40 year career. Mike has suffered from epilepsy for more than 20 years, and in 2017 he was diagnosed with dementia. At the same time, his doctor reported signs of chronic traumatic encephalopathy, or CTE, a degenerative brain disease found in athletes, military veterans and others with a history of repetitive brain trauma. Mike and his wife Kim have founded the Adamle project to provide patients and families living with symptoms of CTE with tools, resources and a supportive community. They are here today to talk about living with post-traumatic epilepsy and CTE.

Kelly: 01:19

Kim, Mike, thank you so much for joining us today and talking about this incredibly important topic that is just not getting enough air time out there. And that is this connection between epilepsy and CTE, the chronic traumatic encephalopathy. And in your case Mike, this is as a result of years of playing football. You have had an incredible career, and this amazing life playing. You played football with the likes of Walter Peyton, and Joe Nemeth, and started your career here in Chicago at Northwestern as an All American. My father was very excited to hear that I was getting to chat with you today. Tell me what are two, or some of your favorite memories that you have from playing football?

Mike: 02:13

Most of the favorite memories are the time spent with the guys that you played with. You forge relationships that last you not five years, not 10 years, but for the rest of your life. We had a group of guys at Northwestern, in my senior year we finished second in the big 10, only behind Ohio State. And back then you either went to the Rose Bowl or no bowl. But we've all stuck together for the last 50 years, believe it or not. I mean, we go to games, and we sit on a guy's back porch that we used to play with then. We call ourselves the hard bodies. Even though we're not so hard anymore. So I mean, I played there for four years. I got drafted by the Chiefs. I played there for two years, got traded to the Jets. I was there with Nemeth, and played there for years and then got traded to the Bearers. My last three years were Walters first three years. So, fortunately we're not

so unfortunately between the 76 and 77 seasons, I had tore my leg water ski jumping, part tore away.

I think it was that NBC, you just started with NBC her in Chicago.

Kelly:	03:26	And it wasn't in your contract that you weren't allowed to do that?
Mike:	03:30	It wasn't. It wasn't. I think I was making about 35, \$40,000 at the time. But Jim Finks, who was the general manager back then and he said, you really freaking pissed me off. I said, you know what? Because we were really counting on you next year and why we traded for you in the first place. But I'll tell you what, you stick around, you get rehabbed, and we'll pay your salary and you can just come back whenever you can and we'll start all over again. But when all that was happening, during the times afterwards, I just said, you know what? They're not going to go anywhere anytime soon. I mean, the Bearers were like 10 years removed from the Superbowl. I mean, it really didn't manifest how good they were until the 80s started. So I knew that I don't want to do this.
Kelly:	04:18	Yeah.
Mike:	04:19	To make a long story short, I did some auditions for local television, and I eventually got hired by NBC in New York. One thing led to another, I was pretty good. I got paired with all this music broadcast personnel that NBC hired. Me and Brian Gumbel did the pregame shows.
Kelly:	04:39	You had an illustrious career.
Mike:	04:39	Yeah.
Kelly:	04:39	40 years in.
Mike:	04:39	Yeah.
Kelly:	04:40	I mean, that's amazing.
Mike:	04:46	Yeah, I'm a really, really, really lucky person. I mean, that's why I'm here today, I guess.
Kelly:	04:54	Yeah. And so, what was the first sign that neurologically something wasn't quite right?
Mike:	<u>05:00</u>	Do we go back to the late 90s?

Kim:

05:04

Yeah. Yeah. Mike: 05:10 Kim: 05:11 So it was like January of 1999. Mike: 05:16 Yeah. I was just on the air, and I remember doing a sportscast; "Tonight the Bulls beat the Portland Trailblazers 97/90. Michael Jordan had 23 points..." And as that was going on, it was like my brain was in half, part of me is saying that, and the other part is like this giant tidal wave is just coming over. And the next thing I knew, I was in my office and I asked some friends, what happened out there? And they said, what do you mean? I said, well, I looked at my shirt, it was dripping wet, and I said something happened there. And the day that it happened, we went over to ... Correct me if I'm wrong here. Kim: 05:57 Well, Larry Wert, the general manager-Mike: 05:58 Yeah. Kim: 05:59 Took him from the newscast directly to Northwestern Hospital. And they checked him in for three days of neurological testing. And that's when he was diagnosed with epilepsy, at that time. And it was Dr. Richard Grosvenor was the neurologist, luckily, who's a specialist with epilepsy, who was. And he was able to identify a lesion on the inner left hemisphere of Mike's brain from the imaging that he attributed to football. And that was causing the seizures. Kelly: 06:36 And were you familiar with the words traumatic brain injury at that point? Mike: 06:41 No. Kelly: 06:41 TBI? Acquired epilepsy? Kim: 06:45 No. Kelly: 06:45 Any of these things. So you received an epilepsy diagnosis and-Mike: Well, the biggest thing was is, it just didn't sound so 06:51 catastrophic back then. Kelly: 06:58 Yeah. Mike: 06:59 But here's this group of people that have epilepsy. Now you've got here, here, here.

Kelly:	<u>07:06</u>	All of these different types of epilepsy.
Mike:	07:08	Yeah, yeah.
Kelly:	<u>07:08</u>	And different causes, because we know that epilepsy in and of itself is a symptom of something else.
Mike:	07:14	Right.
Kelly:	<u>07:15</u>	It is a diagnosis, but it is caused by another condition, be it genetic, or acquired through traumatic brain injuries or the like.
Kim:	<u>07:26</u>	And when the doctor told us, he's giving us the results, diagnosing him with epilepsy, that he had had a seizure. That's what he experienced. And that he had through his imaging and tests had been able to identify this lesion that he said was due probably to a football injury. That was new information for us, because I knew epilepsy as mostly a condition you were born with, and it manifested in the grand mall type seizures. So, this was something new for us. It was the first piece of information that we had about any type of brain trauma related to football.
Kelly:	08:13	And what year was this?
Kim:	08:15	This was January of 1999.
Kelly:	08:19	So that was sort of your first sign, is that something is wrong neurologically, you were having seizures. How frequently were you experiencing the seizures?
Mike:	<u>08:30</u>	It would vary, I guess.
Kelly:	08:36	And were you able to get them under control with medications? Or are you still experiencing breakthrough seizures?
Kim:	08:44	I think it was much like anybody's experience with epilepsy, trying out different medications, different dosages, different things that affect it, like sleep.
Kelly:	08:57	Yeah.
Kim:	08:57	Or lack of sleep.
Kelly:	08:58	Stress.
Kim:	08:58	And stress. So going through all of that, we were able to get it under control going through that process. This wasn't the first

one. I remember him telling me at the time that he had had a few of these in the years previous, he didn't know what they were, because his are not the grand mall. I think they're called what? Complex partial. And so, it's just like he would phase out. And for him it felt like, he mentioned a tidal wave, or he described it as like a train coming at him. They would last a minute or so, maybe. They were short in duration. And he recalled having that experience several times in the years leading up to that major incident on air. But with the doctors, they were able to get it under control. But in the fall of 2015, Mike started experiencing clusters of seizures again. And they did another MRI in that December and then put him in the hospital for another three day complete evaluation, neurological evaluation in January of 16.

play in the pros against the odds when people thought he was too little. And so here he is faced with another life challenge

and he's hitting it head on. And my kid-

Is that pun intended?

No, no.

Kelly: 10:20 When did you learn that this was very likely CT? Mike: 10:26 Well, we had this three day examination and make sure that, the doctor came out, Dr. Michael Smith, and this was just to see how you were doing with your epilepsy. Yeah. Kelly: 10:38 Mike: 10:38 And he said, it looks like you're doing okay, make sure you don't go rogue on us and take your medicine every single day. Don't play Superman or any of that stuff. He said, but we did also find something, symptoms that are concurrent with CTE. And I said, well that's kind of funny, from what I understand is that the only way they can tell that is in post-mortem. I said, well, if that's the case, if you think I've got something that's close to being CTE, and nobody lives from it, well 'll be the first person that lives from it for a while afterwards. Kim: 11:18 I think that's just so symbolic of who Mike is. He's always lived life all out there. I mean look, he's a little guy, 5'9". He was a big 10, All American at Northwestern, which is saying a lot. Mike: Yeah. 11:33 Kim: 11:34 It gets big teams like Ohio State and everything. And went on to

11:48

11:49

Mike:

Kim:

Mike:	<u>11:53</u>	It's a trap door, you've got to-
Kim:	<u>11:59</u>	So, I think for Mike it was to show, your life isn't over.
Kelly:	<u>12:05</u>	Right.
Kim:	12:07	That's Mike's attitude. He has a zest for life. He's going to show, there's no cure for CTE, but your life isn't over. This is how you live with CTE.
Brandon:	12:18	Hi, this is Brandon from Citizens United for Research in Epilepsy or Cure. To learn more about advances in our understanding of post-traumatic epilepsy, as well as the exciting new therapies being developed that may one day result in a cure. Visit cureepilepsy.org/PTE for more information. Now back to this episode of Seizing Life.
Kelly:	12:38	Diving a little deeper into CTE, what are those symptoms?
Kim:	12:44	Typically, you start with some memory issues, and it moves into some affective issues, some depression, there's rage, paranoia, aggression, impulsivity, executive functioning is impaired. Executive functioning is your ability to initiate, to plan, to organize and then to execute things.
Kelly:	<u>13:12</u>	That is another huge thing with epilepsy.
Kim:	<u>13:12</u>	It's in everything we do.
Kelly:	<u>13:17</u>	And seizures.
Kim:	<u>13:18</u>	Yes.
Kelly:	<u>13:18</u>	It's very, very common. Has there been a correlation? Have there been studies between CTE and epilepsy?
Kim:	<u>13:26</u>	They're just really starting to research CTE. And so as we're dealing with the epilepsy and looking at it in light of how does this all work together? I don't know of any studies. I'm not a medical professional, but I did contact Dr. Chris Nowinski, who's the CEO of the Concussion Legacy Foundation to ask him, what do we know about the incidents of epilepsy with this type of acquired brain injury? And he says, I don't know of any studies on it. So, I don't know what the statistics are. What I do know is that just through our interactions, I'm a part of the NFL, it's a private wives group, over 2,500 wives. And we women, we network, and so we get a lot of good information sharing

amongst ourselves. And just a question came up in the past week, a wife wrote in whose husband was experiencing some really problematic, worrisome behavior. And somebody brought up, is he having seizures? And it started a whole thread of discussion. And women were talking about their husbands having seizure conditions, or this type of what looked like a seizure but it hadn't been diagnosed.

Kelly: <u>14:50</u>

How do you raise that awareness so that people can ... Because you have done an incredible job continuing to live your life, getting out there, and taking care of your physical health, taking care of your mental health, doing everything that you personally could to live the best life possible for you and your family with CTE. How do you live with it? How do you treat it? How have you made the most of your life with this probable diagnosis?

Mike: 15:25

We have found that things that improve cognitive functioning are really, really, really helpful. And there are things that are at your disposal anytime you want to turn on the music. Like ballroom dancing. First of all, you forget all the stuff that might be happening to you, but because you have to memorize left.

Kim: 15:49

Well yeah, so the ballroom dancing is one example of something that we do that's a type of therapy. It's good for the brain. And the reason is, is that it has multiple components of what research has shown to be healthy for the brain, and things that actually ward off dementia, and improve your cognitive functioning. So for ballroom dancing for instance, you've got the physical part, where you're moving, you're dancing, it's a workout. You watch these pro players when they do Dancing With the Stars, it's a workout. So you get the physical workout. We know that physical exercise is good for the brain. You've got the cognitive part, your brain is operating on so many levels. You're remembering the step, you're dancing in partnership with somebody. So you're judging. Leading, if you're the guy, and how to lead and responding to the woman. The woman is responding to the man. So your brain is operating on that level. And then you've got the social component. We've found socialization, social interaction is crucial to wellness and brain health.

Kim: 16:55

So, that's firing up the brain on all kinds of ways and you get those endorphins flooding your brain, and then you add in music. And music is another thing that we know that just gets those synapses firing in all kinds of ways. And especially with memory, and they found in studies utilizing dancing and music, that if you play music that is from your era, is when it's especially powerful. It just ignites so many memories and parts

of the brain that are maybe lying dormant. So it gets them all active again. So ballroom dancing is one thing. Exercise and the types of exercise. Cognitive stimulation and what that means. Social interaction, diet and nutrition. And then positivity, and keeping, your hopes alive. And across all that of course there's good medical care overseeing it all. But when you talk about cognitive stimulation, basically what you want to do is engage in new learning. Because when something is easy to you, or comfortable, you're not learning, you're not growing the brain. So you want to engage in new things, novel things. So learn a new language, take up a new hobby, ballroom dancing, you're constantly challenging yourself.

Kim: 18:19 These are the types of things that really improve cognitive functioning. What our MO was, there's no cure for CTE. We cannot stop the ongoing deterioration of the brain. That's ongoing. But what we can do is encourage neurogenesis. So, that's new cell formation. And we can do things that exploit the neuroplasticity of the brain. So new pathways where other parts had been destroyed, or memories destroyed, we can create new pathways. And that's through experience. So the diet that we did is an antiinflammatory. So low sugar, low glycemic index, good quality protein, lots of antioxidants, and the fatty acids and omegas. So you have blueberries, and steel cut oats, and broccoli, and salmon and olive oil. So we are creating like a tool kit.

Kelly: 19:18 Yes.

Kim: 19:18 We can't treat it, we can't stop it. But here's what you can do.

> And we have just in this past year, the World Health Organization, WHO, came out with their guidelines, a whole book where they did a meta analysis of the research out there that speaks to brain health, and mild cognitive dysfunction, and warding off dementia. But the things that they found that were effective were exactly these things that we're doing. It's the things with exercise, with good diet, cognitive stimulation and learning, and with social interaction, and sleep. Sleep. Good

sleep.

Mike: 20:07 It's probably the number one thing for everybody.

Kelly: Yeah. Absolutely. 20:08

Kim: 20:11 So, this is our other message for hope. This is Mike's lifestyle. This is how he lives his life. But for the people who contact us, we hear from a lot of, not only the effected men, primarily, but

a lot of mothers. We just spoke with a mother yesterday, a

young man, her son's in his 30s. Wives we hear from, and not a lot of hope, and a lot of despair, because the symptoms of CTE are devastating and extreme, chaotic, and it affects the whole family. So they're desperate. And so, part of giving hope is, here's what you can do.

Kelly: <u>20:56</u> Right.

Kim: 20:57 Here are things that can make a difference. And we can support

one another. That social interaction, telling your story, being there for somebody else, joining hands, giving hope to another, until they find a cure, and they will find a cure, and they will find

a treatment.

Kelly: You are speaking my language verbatim. Yes, all of that. I feel all

of that to my core. This has been just so incredibly enlightening, and I have learned so much from both of you, and I am so grateful that you came and spoke with us today and shared your story. Mike, Kim, thank you for being here. And I wish you both

the absolute best in the years to come.

Kim: <u>21:43</u> Thank you Kelly. Thank you.

Mike: <u>21:44</u> Yeah, thanks a lot.

Kelly: 21:48 Thank you Kim and Mike for sharing your story and experiences

battling post-traumatic epilepsy and chronic traumatic encephalopathy. Traumatic brain injury resulting in post-traumatic epilepsy, or PTE, is a common cause of epilepsy that can happen to anyone who has experienced brain trauma from an accident or head injury. Cure has a research initiative dedicated to increasing our understanding of post-traumatic epilepsy as a result of traumatic brain injury. For more

information, please visit cureepilepsy.org. Thanks so much.

Brandon: 22:27 The opinions expressed in this podcast do not necessarily reflect

for general information only, and does not offer medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals who are familiar with individual medical conditions and needs. Cure strongly recommends that care and treatment decisions related to epilepsy and any other medical condition be made in consultation with a patient's physician or other qualified healthcare professionals who are

the views of Cure. The information contained herein is provided

familiar with the individual specific health situation.