Chris Semsarian – 'What Makes Your Heart Stop'

Moderator: Welcome to the Podcast series of *Raising the Bar Sydney*. Raising the Bar in 2016 saw 20 University of Sydney Academics take their research out of the lecture theatre and into 20 bars across Sydney; all on one night. In this Podcast, you will hear Chris Semsarian's talk, *What makes your heart stop?* Enjoy the talk.

Chris Semsarian: Thank you very much and it's a pleasure to be here and thank you to Harpoon Harry's for hosting us and thank you to the University of Sydney for this wonderful initiative and bringing research and medicine to the community and what better place to do it then in the pub.

What I'd like to do is tell you a little story I guess in terms of how we've learnt so much about sudden death in young people and heart disease in young people. So normally when you think of heart disease, you think of someone like me. Someone who perhaps - I'm not quite 50 - but in their 50's, overweight, sitting in front of a television watching sports all day, high cholesterol, high blood pressure, blocked arteries, that sort of situation.

So you expect that when you think about heart disease. That's the image in your head. But what you don't often think of is someone like Usain Bolt who might have a heart condition that might kill him. Or a young person in their teens or in their 20's who playing a game of basketball or football might die suddenly on the football field or the soccer field. You don't think a young person like that would have heart disease. But that's what we've learnt so much about in the last 20 years. Why do young people get heart disease? Can we understand what they have? And most importantly, how can we prevent this happening in the community so that these deaths never occur?

And I'll start with a very simple story. About 18 years ago when I first was starting my training in medicine, I came across a father and a mother. They were in their 50's and they came because they'd just lost their son. Their son was a 23 year old boy; he was running along the beach in the Central Coast of New South Wales. Previously well, no issues of his health, fit, healthy guy, collapses on the beach and dies. So the parents came that day and asked me as a doctor, what can we do? Why did my son die? I've got other children, how can I stop that happening again to my other sons and daughters? And I had no idea. I had no answers at all. So when you have no answers you think, well there are answers, but I just don't know them. I'm still a young chum, I don't know, I haven't learnt, I haven't followed that chapter in the book. So I actually went away and looked up all the literature, all the books and all the articles in the literature and there was nothing. There was actually no explanation why young people die suddenly and why this happens in our communities so regularly.

And so that was my inspiration to say, well we know a lot about blocked arteries and smoking and blood pressure and cholesterol. That's sort of the easy part of medicine, of heart disease. But we don't know much about why young people die suddenly.

So what is it all about? And that's sort of the next 16 years is what we've been working on and trying to understand these things. So why do young people die suddenly?

Well we need to learn a little bit about the heart. So the heart is basically a pump. The job of the heart is to pump blood and that's its primary purposes. And for it to pump it needs an electrical system to power it up and allow it to pump.

So why do young people die suddenly? They die of heart conditions which can affect either the muscle of the heart which we call cardiomyopathies or heart muscle problems. Or they can die of electrical rhythm problems of the heart and you might have heard of things like Long QT Syndrome, Brugada Syndrome, other conditions like that.

But why would a young person get these diseases when they're fit and healthy and active and they go to the gym all the time and they do all those things, all the right things? Well it's in their genes and that's what we've sort of learnt in the last 15 years or so. So each of us have, how many genes? How many genes do we have? Sorry that's not to pick on people, have a guess, speculate. Don't look at your partner or whatever, just give us an answer. How many genes do we have?

Audience: Forty-six.

Chris: Well that's not fair, because she's from my group, she's my PhD student so she knows the answer and luckily she's correct. Otherwise you'd have no job tomorrow. We have 22,000 genes. And why am I saying that? You have 22,000 genes for all sorts of reasons. The gene that makes the colour of your eyes blue or brown, the genes that make you an athletic sort of person. The genes that you've inherited from your mum and dad. All sorts of things. We have 22,000 genes. What's been amazing is that only ten years ago, to analyse one gene it took about one year. So if I wanted to have a look at one of your genes, it would take me one year of research to work out what that gene sequence is. Today I can take James' blood, in fact I can get his cup and scrape some cells from his cup and sequence his DNA all 22,000 genes in about two weeks. That's the advance. The advance has been this incredible technology where we can sequence all our genetic makeup all in one little test. And it's called the whole genome or a whole exom.

So why am I telling you that? I'm telling you that because in the discovery of 22,000 genes, we're starting to understand what the heart genes are and at the moment we've probably found about 200 heart genes, faults in which, and they're like spelling mistakes in the genes, lead to heart diseases in young people.

So the other conditions of the heart like high blood pressure, cholesterol develops over many years so you don't get it until your 40's or 50's. These genetic heart conditions you're born with the gene fault. So you're actually born with it and it develops usually in your teenage years or in your 20's. And they're the people that you see on the news who have died suddenly playing sport or football or cricket or whatever it might be.

So we've learnt so so much more about the underlying genetic causes of heart disease in young people and by doing so we've worked out that almost every genetic heart condition, whatever it is, and we know of at least 40 different genetic heart conditions, we know that all of them as a complication can get sudden death.

So it's a major problem. It's not a common problem because heart disease in young people is much less common than old people with blocked arteries, that's the most common by a million miles. But the problem is the young otherwise well individuals who's tragically in about 50% of young people who die suddenly, that's their first presentation. So it's not like older people where they get some chest pains or they might get some shortness of breath. They might get some palpitations, they might get some you know feeling unwell or blackouts. In young people the first presentation of their disease can be sudden death. And that's the real tragedy.

So these are children who have gone to school and don't come home. We never send our kids to school not expecting them to come home. That's crazy. These are kids that will go to sleep and in the morning the alarm clocks going off, the mother walks in because they think their teenage son is just lazy and in bed but he's actually deceased. These are the most tragic circumstances. But the hope and I guess the inspiration we have is through these deaths we've learnt so much about young people's heart disease and now we're beginning to prevent heart disease and prevent sudden cardiac death in our communities. And that's the message that I want to convey to you tonight and I want to go into it a little bit, that through research, through those tragic deaths, we've learnt so much about young people and heart disease and now we can start to prevent it.

And that's the journey we have in research, that's the journey we have in identifying a clinical problem. Those two parents that I saw 16, 18 years ago, I've seen them, there was a big deficiency in our research, we had no idea and now we've spent the next 16, 18 years to learn more about it.

So how can we stop people dying suddenly? And that's what I want to focus on from here on. So we can stop people dying suddenly at an individual level. So you might be sitting here, I've noticed you've been a bit uncomfortable in your chair because you're starting to think maybe I've got one of these heart conditions or something. You've just been a bit edgy and moving around and I don't know if you need to go to the bathroom or whatever, but you've been a bit edgy and so I'm going to tell you a few tips.

So the problem is, as I said to you already, about 50% of young people who die suddenly, we don't believe they have any symptoms beforehand. But when we've done some more research, we've actually identified some symptoms. So there are some warning signs and there are basically two things that are very important in young people. The first is if you're getting blackouts. Now everyone faints, you can call it a faint or a blackout or a collapse. But if they're happening in unexplained situations, you're crossing the road and you have a blackout. You're driving a car and you have a blackout. You have a blackout after playing sports. That can be a warning sign for one of these underlying heart conditions and you should have some basic heart test to see if there is any evidence of any of these genetic heart conditions.

The second thing is that your family history is really, really important. And if you don't know your family history, I know it's sort of a boring thing to do, but I'd try and get it one day because it's really important. Especially when your mum and dad are still alive and they know their history. It's amazing what things come up in the family history and what we look out for is sudden death in a young person in the family. So it might be a drowning, of a cousin who was 15 years of age. You dig deeper a bit further into it and you find out that that 15 year old could swim perfectly but for some reason drowned. And so that's a suspicious event in the family. And if you have a family history like that or a parent that's died in their 20's or 30's or anything like that, what we call a premature sudden death in a family member, you need to be a little bit suspicious that there may be a heart condition in the family and I suggest getting some basic evaluation and testing.

So, and family histories are tricky because sometimes heart diseases are disguised. So what do I mean by that? I mean things like motor vehicle accidents of young people. The person's a driver, the car crashes and the post mortem result says the cause of death was a motor vehicle accident. But when you dig into that, sometimes you see well they were only driving for 20 minutes.

They were in the middle of the day on a straight road so why would they have a motor vehicle accident necessarily. Maybe they had some heart issue that made them blackout or had a rhythm problem and that led to their crash. So any family histories, drowning, unexplained motor vehicle accidents are very important to try and dig into and if you've got a strong family history of any of these events I think it's a very good idea to get a very basic check up to make sure your heart is okay. When I say basic heart check up, basically what I'm talking about is an ECG which is the electrical trace of the heart and secondly the echocardiogram or the ultrasound of the heart.

So two very non-invasive tests, I haven't offended you have I?

Audience: No (11:23).

Chris Semsarian: Okay, you're not going to another talk are you? Because this is the best talk, right. All right, all right, you're okay. You're forgiven. Is that the truth? It's the truth, okay. He says "No no no, it's all good". So how can we prevent sudden death in an individual? Firstly knowing your family history, secondly if there's any blackouts, that's very important.

If we know someone in this room has a heart condition that can lead to sudden death, the other thing is we can do a lot to prevent sudden death and stop sudden death. How do we do that? It might be something as simple as lifestyle modifications. So you might have heard that in some of these heart diseases we tell them to avoid the highest level of competitive sports because high level sports can trigger rhythm problems of the heart. We might give them tablets such as beta-blockers, which might protect the heart against rhythm problems. And thirdly we have an amazing discovery which I, this is my show and tell part of my talk. Who knows what this is that is not a medical student?

Yes sir?

Audience: I think it's (12:35).

Chris Semsarian: Close. It's half a pacemaker.

Audience: (12:37).

Chris Semsarian: Yeah you don't have to Google it, I'm going to tell you the answer. It's all right.

Audience: I'm taking notes.

Chris Semsarian: Oh you're taking notes? I'm honoured. That's awesome, it's being recorded I think, it's going to be a podcast, so it's going to be downloaded a million times I'm sure in the next 24 hours. This is what's called an implant, I'll pass it around, this is called an implantable defibrillator. So you all know what a defibrillator is and we're going to talk about that at the end. That's the thing when we put the paddles on the chest and we shock the heart. And I heard an amazing inspirational story of one of the gentleman here who saw this in action at an airport recently in Adelaide. The paddles on the chest and you shock the heart.

This is the same thing but it's an internal device. So what we do is we make an incision, we implant this under the chest and a wire comes out and goes sits inside the heart.

So its job is really simple. It just monitors the heart. It monitors every beat of the heart, 24 hours a day, seven days a week. If the heart goes to slow it paces the heart. That's why I said you were half correct, it paces the heart. But what we implant this device for is not actually for that, it's if the heart goes too fast and can lead to cardiac arrest and sudden death.

Audience: (13:59).

Chris Semsarian: Yeah that's a very good question. So what you normally do is you don't go through the main x-ray place. You tell them you've got a device, we give you a card, you show them the card and they'll wand you with a wand so they avoid this area because magnets can affect the function of this.

So what this device does is if your heart goes into an abnormal rhythm it will actually charge up and deliver a shock directly onto your heart. So these are lifesaving devices. These are automatic, so you don't have to think, I'm not feeling well, I'd better charge it up because it's going to shock my heart or something. It's automatic. It's there. Some patients call it their life insurance policy or that sort of thing or their guardian angel because it protects them against this problem.

So these devices which I'll hand over and they're about $30,000 but before you think about pocketing it, you can't actually use that one because it's not sterile so you can return it back. But just to get a feel, this is a device which is stopping people dying suddenly at all ages, but our particular benefit is in the young people with heart disease.

So that's at the individual level. What we can do is look at the family history, look out for symptoms and if we can identify people at risk of dying suddenly, we can implant devices, we can put them on medications and we can also monitor their heart rhythms etcetera on a regular basis.

So that's one approach but hand in hand with that approach is our public health approach to prevent sudden death. And there's basically two things that every Australian should know how to do. What do you reckon the first one is? Very quiet in this corner here. Advance life support. So what would you say every Australian should know how to do, what would be your …?

Audience: CPR.

Chris Semsarian: CPR, yeah. So CPR stands for cardio pulmonary resuscitation. So that's when somebody has, if I have a collapse on the ground right now, I hope somebody will come to me and start CPR straight away. My PhD student is saying no, which is really disappointing. So the first thing to do is CPR. Who knows how to do CPR?

Audience: It changes every year.

Chris Semsarian: Yeah I'm going to tell you the answer right now, that's exactly right. So you've done it before?

Audience: Yeah.

Chris Semsarian: Yep.

Audience: (16:18).

Chris Semsarian: Yep so very important right? So if somebody collapses or something very important.

Audience: (16:21).

Chris Semsarian: It does change but it won't change anymore, I'll tell you why in a minute. I think we're at the final point. Who wants to put their hand up and sit (16:28). So where did you learn to do CPR?

Audience: (16:33).

Chris Semsarian: Excellent, so medical field sir?

Audience: Medical student as well.

Chris Semsarian: Medical student as well. Okay. So I'm trying to propose to at a Government level that every Australian learns how to do CPR. Everyone gets trained to do CPR. There are some places in the world where they're very clever with this so you can't get a driver's licence in Denmark or some of the Scandinavian countries until you've learned a CPR course. In Australia at Year 9 most kids are supposed to learn as part of their syllabus how to do CPR as well. But we need to make it at the forefront. People forget how to do it, it changes and all those sorts of things. So here's the deal. Everyone needs to learn how to do CPR. Who's heard of the song *Stayin Alive* by the Bee Gees? Who hasn't heard that song? Because if you haven't, you're a loser. You've been sitting under a rock for the last 40 years.

Okay Bee Gees *Stayin Alive* yeah? So of all the songs available they worked out that the Bee Gees rate, the beat, is exactly how fast you should do CPR. Okay? So think of *Stayin Alive* in your head as you're doing CPR. That's number one.

Number two. Who still does mouth-to-mouth with CPR? Nobody. So mouth-to-mouth was one of the biggest obstructions to people wanting to do CPR. So someone would collapse and they'd get on the chest and they'd go, "I don't really want to put my mouth on there. They've vomited and blah blah". Now it's not part of CPR anymore. So you don't have to do any mouth to mouth at all. So CPR in 2016 and it won't change is what we called hands only. So hands on CPR. And at about 100 beats per minute for an adult and if you can't remember that, then *Stayin Alive*, so keep that in your head.

So the British Heart Foundation have actually set up a little ad, if you don't believe me, look up British Heart Foundation *Stayin Alive* and they've got a beautiful educational video of how to do CPR and it's all about *Stayin Alive*.

So every Australian should learn how to do that and if you can do that I guarantee you at least once in your life you'll use it. Because we just know statistically there's so many sudden deaths at various ages that you will come across one one day.

So CPR is extremely important and the second thing is defibrillators. So I told you about the little device, the implantable defibrillator, but what we need to have in all of our communities is public access to defibrillators. So defibrillators should be everywhere.

So if you go to the shopping centre these days, in Westfield Shopping Centres, there's defibrillators everywhere. If you go to the airport, if you go to many schools. All public places, sporting grounds, should have defibrillators everywhere. And Australia I think are doing a pretty good job but they're a little bit behind the rest of the world in terms of getting these defibrillators. They're only about $2,000 and you almost would mandate that any RSL club, any sports club, every oval, every school should have one of these devices. Because they are life saving.

So how do you ensure you save someone's life? What's the most important things that need to happen if you're going to save me when I've collapsed on the ground? It's early CPR, somebody jumping on my chest and doing the compressions and secondly either getting a defibrillator from as close as you can to here and shocking my heart or trying to do that and calling an Ambulance at the same time. You should probably call the Ambulance as you're walking towards me and say "Somebody call me an Ambulance", but in the city you'll be waiting for a little while.

So early CPR and early defibrillation gives you the best chance of survival after a cardiac arrest. And what do I mean by that? Seconds count a lot. So every minute that passes by while I'm lying on the ground, my chance of survival drops 10%. Turn five minutes I've only got a 50% chance of surviving. By that time I'm usually going to have brain damage as well. So minutes count in cardiac arrest and I think this is what we need to teach our communities, that CPR is important. That defibrillators are important and we need to all learn how to use those things. Defibrillators these days, you just open the lid and it tells you what to do. A child can use it. A twelve year old and use it. A ten year old can use it. It says put the paddle here, put the paddle here, stand clear. So as long as a child can understand basic English, then it's very easy to use.

So what I hope to have told you and I'm going to open up to questions, what I hope to have shared with you tonight is, firstly young people can die suddenly from heart disease. I know it's hard to believe, people are suspicious. The number of families I see where the rest of the family think, oh there was a drug overdose because they don't believe that a young person can have a heart condition. So was it a drug overdose? Were they poisoned? Was it some foul play in action? So it's really really important in that situation to make sure that we make as best effort as possible to find out why these young people are dying suddenly and what I'd like to share with you is that in 15, 16 years we've learnt so much about why young people die suddenly. What the role of genetics is and how we can ensure that by looking at people's genetics we might be able to pick who's at risk of dying suddenly. And thirdly we can already stop people dying suddenly if we firstly know who's at risk and then secondly doing public health strategies like public access to defibrillators, teaching people how to do CPR.

I'll give you a very short story to end. Mike Baird's pretty unpopular at the moment isn't he? But he's a good guy as well as one of the issues I had was, we had a young boy, a 16 year old boy who died suddenly at a school in the Sutherland Shire. The family came to me after a while and they said, "Chris, we've got a problem". And I said "What's the problem?" And they said "We actually raised money to put a defibrillator in the school because there was no defibrillator in that school". And they said "We gave it to the principal and the principal said we can't take it". And I thought, that's crazy. This is a life saving device, you can't take the … they're giving it to you, they're not even paying for it. They said no the schools are not allowed, this is public schools, not allowed to have defibrillators in the school. "Why"? "Because the teachers are a bit stressed about using them. If they have to use them" and all this sort of stuff.

Who is going to maintain them. I couldn't believe it, I actually didn't believe it. I said "Fine I'll look into it". And it turns out the law in New South Wales is that New South Wales public schools can't have defibrillators. Private schools can but public schools can't. So my encouragement to you is never give up on these things because you're going to end up fighting a cause that's going to save people's lives. So I thought I'll just email Mike Baird and see what he thinks and to his credit he got his Secretary of Staff or whatever it's called, his main right hand man to contact me. Then we had a 45 minute meeting face-to-face and I just told them exactly the story I told you but I also went into his office with a defibrillator and I said, "Look at this" and opened it up and it was simple to use. And to his credit he couldn't believe that a law existed where you can't actually have defibrillators in schools. Bizarre. For those of you that don't know, he's a lifesaver as well. Works on Manly Beach, understands cardiac arrest. And so they overturned that rule in December of last year.

So my encouragement to the younger people in the audience is never give up on these causes. Now you think you can never fight such a cause but never give up on it. I think that one rule change will save the lives of a few children every year. It might be parents who are picking up the child or bringing the child home that might have the cardiac arrest. So it might not be the child, it might be one of the parents. But the important thing is that we are now at various different angles trying to improve how we manage sudden death in the young and hopefully through measures like that and learning, everyone learning CPR and ultimately, my biggest goal is actually to correct these diseases by gene therapy. If we know there is a genetic fault in these conditions, well there's an option to try and correct that gene abnormality and cure the disease and that's the sort of the ultimate goal of all this work.

So I might leave it at that point, I think I've gone around 25 minutes so I think that's what I was supposed to do and now I'll be happy to answer any questions and comments if you have comments, please do.

Moderator: Right before we start with the questions let's give Professor Chris a round of applause.

Thank you for listening to the Podcast series of *Raising the Bar Sydney*. If you want to hear more Raising the Bar talks, head to www.raisingthebarsydney.com.au

End of Recording.